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Social Security Experience Panels: Who is in the panels and their experiences so far



EQUALITY, POVERTY AND SOCIAL SECURITY



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Introduction

In May 2018 Social Security Experience Panels members were invited to take part in a survey to help us:

- Ensure their personal details are kept up to date
- Understand more about the demographic make-up of the panels
- Understand what is working well for Experience Panels members, and how we can improve their experience

915 people responded to the survey, which closed on 31 July 2018. The responses were combined with existing information about the demographic make-up on the panel collected as part of the “About Your Benefits and You” survey in 2017.

The purpose of the Experience Panels research is to inform the development of the new social security system in Scotland. Scottish Government is committed to the principle of co-design in this process. This research provides valuable demographic information about our respondents to inform how Scottish Government can engage with different groups when developing the new social security system. It also provides an overview of feedback from respondents about taking part in the Experience Panels and how we can improve this experience for them.

These findings will be used to help consider how we will engage with groups that are less well represented on the panel, and to consider how we can continue to improve our approach to be as inclusive and supportive to panel members as possible.

The findings below relate to those panel members who responded to this survey, not to all panel members. We will re-run these questions regularly with the aim of increasing the proportion of panel members we have demographic information on.

Key findings

- 63 per cent of respondents identify as “female” or as a “woman or girl”. 35 per cent identify as “male” or as a “man or boy”.
- Almost three quarters of respondents are over the age of 45. A quarter are over the age of 60.
- 96 per cent of respondents describe their ethnic group as white, and 2 per cent said they were part of a minority ethnic group.
- 51 per cent of respondents said that they had no religion. 18 per cent said that they were Church of Scotland, and 11 per cent said they were Roman Catholic. A number of other religions were represented among respondents, ranging from 1 to 3 per cent of respondents.
- 86 per cent of respondents identified as heterosexual or straight. Nine per cent identified as lesbian, gay or bisexual and two per cent identified in another way. Less than 10 identified as trans (or transgender).

- 83 per cent of respondents said that they had a disability or long-term health condition.
- 49 per cent of respondents said that they have caring responsibilities and 49 per cent said they do not.
- Key areas that panel members described as working well included feeling listened to, feeling able to contribute to the design of the new social security system, and feeling that they had a choice about how to take part
- Key areas panel members felt could be improved included having more events across different parts of Scotland and offering more alternative times and ways of participating for face-to-face events.

Background

The Social Security Experience Panels were established to ensure that the design for the new social security system in Scotland is shaped by the experiences, needs and priorities of those who will use it. Over the course of the development and introduction of the new system, panel members are participating in longitudinal research and service testing activities to help Scottish Government develop a system that works and that can be continually improved.

The panel is made up of more than 2,400 people in Scotland with experience of the current social security system as it relates to the benefits being devolved to Scotland. This includes individuals who have claimed on their own behalf, as well those who have helped or cared for others.

From May to July 2018, panel members were invited to participate in a survey “About You – keep us up to date with your information and help us improve” (referred to as “About You” in this report). This survey was to help us understand more about who is on the panel, and how we can ensure they have a positive experience. This consisted of a survey to gather valuable demographic information as well as details of their experience with the Experience Panels project so far. All questions were optional. This information was added to the demographic data that was collected as part of the 2017 “About Your Benefits and You” survey.

Some demographic data – specifically ethnic group, religion and belief, sexual orientation and gender identity - were asked for the first time in this 2018 survey. These questions were removed from the 2017 survey at the user testing stage, as panel members told us they were not comfortable sharing this information at that stage. Now that we have built trust with panel members over the first year of the project, we have added these questions back in.

Methodology

The “About You” survey was carried out between May and July 2018. Responses were collected as paper submissions, online, or through a phone call. Accessible formats were available and respondents could provide additional information on request.

The 915 survey responses were analysed alongside demographic information collected during the “About Your Benefits and You” survey from 2017, which had 1,144 unique eligible respondents. All personal identifiable information is held in a separate secure file.

Data has been cleaned and analysed by Scottish Government researchers. The data has not been weighted due to a lack of publicly available information about a comparable population. The information provided in this report must therefore be understood as being representative of these respondents only, and assumptions cannot be drawn on the wider applicability of these findings to panel members as a whole or for those with experience of the social security system in general.

About the respondents

Age and gender

Questions on age and gender were asked in both the 2017 “About Your Benefits and You” survey, and the 2018 “About You” survey. The information presented in this section reflects the combined data available about panel member’s age and gender across both surveys. 63 per cent of these respondents identified as “female” or as a “woman/ girl”, 35 per cent as “male” or as a “man/boy”. Fewer than 10 of these respondents identified in another way so unfortunately information about this group cannot be published to avoid the possibility of individuals being identified.

One per cent of these respondents preferred not to say their gender, and one per cent did not complete this question. Due to the small number of people who responded this way, the breakdown of these groups by age have not been included in the table below.

Almost three quarters (74 per cent) of respondents were over the age of 45. A quarter (26 per cent) were over the age of 60. Table 1 provides an overview of respondents by age and gender.

Table 1: Complete respondents by age and gender (n=1272)

	Female	% Female	Male	% Male
15 or under	<10	0%	0	0%
16-24	10	1%	<10	0%
25-44	201	16%	79	6%
45-59	384	30%	216	17%
60-79	188	15%	135	11%
80 or over	<10	0%	<10	0%
Total	795	63%	441	35%

Ethnic group

We asked panel members about their ethnicity during the 2018 “About You” survey.¹ 922 people responded to this question. As responses were low across a number of ethnic groups, these responses have been treated as “white ethnic groups”, “minority ethnic groups” (non-white) and “prefer not to say”.

Table 2: Respondents by ethnic group (n=922)

	Number of respondents	% respondents
White ethnic groups	883	96%
Minority ethnic groups	22	2%
Prefer not to say	17	2%

Religion and belief

We asked panel members about their religion and beliefs during the 2018 “About You” survey. 924 people responded to this question. 51 per cent of respondents said that they had no religion. 18 per cent said that they were Church of Scotland, and 11 per cent said they were Roman Catholic.

Table 3: Respondents by religion or belief group (n=924)

	Number of respondents	% respondents
None	469	51%
Church of Scotland	164	18%
Roman Catholic	105	11%
Other Christian	89	10%
Muslim	<10	1%
Buddhist	<10	1%
Jewish	<10	1%
Pagan	24	3%
Another religion or belief group	27	3%
Prefer not to say	25	3%

¹ We used the Scottish Government core and standardized survey question that relates to ethnic group and religion, as a question that is well established and has been tried and tested across a number of Scottish Government surveys. The wording for this question can be viewed here: <https://www.gov.scot/Resource/0051/00514576.pdf>

Sexual orientation and gender identity

We asked panel members about their sexual orientation and gender identity during the 2018 “About You” survey.

86 per cent of respondents identified as heterosexual or straight. Nine per cent identified as lesbian, gay or bisexual and two per cent identified in another way.

Table 4: Respondents by sexual orientation (n=925)

	Number of respondents	% respondents
Heterosexual/ straight	799	86%
Gay/ lesbian	46	5%
Bisexual	33	4%
Identify in another way	18	2%
Prefer not to say	29	3%

98 per cent of respondents said that they do not identify as trans. Less than 10 said that they do, and 2 per cent said that they would prefer not to say.

Disability and long term health conditions

Questions on disability and long term health conditions were asked in both the 2017 “About Your Benefits and You” survey, and the 2018 “About You” survey. The information presented in this section reflects the combined data available across both surveys.

83 per cent of respondents said that they had a disability or long term health condition.

More than half are physically disabled (53 per cent), suffer from chronic pain (52 per cent) or have another long term condition (56 per cent). Almost two in five (37 per cent) have a mental health condition. Table 5 provides details of respondents by disability or long term health condition.

Table 5: Respondents by disability or long term health condition (n=1275 for all categories except mental health condition, mental health condition, n=1117)

	Number of respondents	% respondents
A physical disability	672	53%
Chronic pain lasting at least 3 months	669	52%
Another long-term condition	715	56%
Mental health condition	430	38%
Deafness or severe hearing impairment	113	10%
Blindness or severe vision impairment	86	7%
A learning disability	101	8%

In the 2018 “About You” survey, we also asked respondents about how their disability or health condition affects them.

Table 6: Respondents by disability or long term health condition (n= 742)

	Number of respondents	% respondents
Mobility (for example walking short distances or climbing stairs)	570	77%
Stamina or breathing or fatigue	456	61%
Dexterity (for example lifting or carrying objects, using a keyboard)	345	46%
Memory	331	45%
Learning or understanding or concentrating	270	36%
Hearing (for example deafness or partial hearing)	107	14%
Socially or behaviourally (for example associated with Autism, attention deficit disorder or Asperger’s syndrome)	100	13%
Vision (for example blindness or partial sight)	96	13%
Another way	59	8%
None of the above	26	4%

Caring responsibilities

Questions on caring responsibilities were asked in both the 2017 “About Your Benefits and You” survey, and the 2018 “About You” survey. The information presented in this section reflects the combined data available across both surveys.

49 per cent of respondents said that they have caring responsibilities and 49 per cent said they do not. The remaining respondents either stated that they preferred not to say, or did not respond to the question.

Of those who had caring responsibilities 24 per cent said that they cared for a child or children with a long-term physical condition, mental ill-health, or a disability. 77 per cent cared for an adult or adults with a long-term physical condition, mental ill-health, or a disability, and 35 per cent cared for an adult or adults who need support due to old age.

Experience of benefits

Questions on people’s experiences of different benefits were asked in both the 2017 “About Your Benefits and You” survey, and the 2018 “About You” survey. Table 7 reflects the combined data available across both surveys.

Respondents include those who are currently, or have previously, applied, got, challenged or appealed a decision for one of the relevant benefits, including those who have helped someone else. It should be noted that many people on the panel have experience of more than one benefit, particularly with the transition from DLA to PIP.

Table 7: Respondents by benefit type (n=1275, IIDB, n=1,145)

Benefit	Number of respondents	% respondents
Disability Living Allowance	859	75%
Personal Independence Payments	849	74%
Carers Allowance	476	42%
Winter Fuel Payments	388	34%
Cold Weather Payments	379	33%
Discretionary Housing Payments	310	27%
Attendance Allowance	245	21%
Universal Credit	274	24%
Severe Disablement Allowance	222	19%
Scottish Welfare Fund	228	20%
Funeral Expenses Allowance	116	10%

Sure Start Maternity Grant	103	9%
Industrial Injuries Disablement Benefit	73	6%

Experience of taking part in the Social Security Experience Panels

Panel members were also given the opportunity to feed back on what is working well, and what could be improved about participating in the Social Security Experience Panels. This sections outlines the key themes which arose in response to these questions – all quotes are from panel members who responded to the 2018 “About You” survey.

What is working well

There were a number of key areas that panel members felt were working well. A key theme from many panel members was that the Experience Panels has made them feel listened to, and that they value being able to participate in creating a new social security system for Scotland. Other areas they felt were working well included the choice of how to take part, how surveys and face to face sessions are structured, being kept up to date about the changes to the system, and feeling listened to and able to participate in creating the new system. Other comments included that people enjoyed the opportunity to meet people who may have had similar experiences to them, and that staff were friendly and helpful.

Feeling listened to

A key theme from many participants was the value of feeling listened to and the opportunity to participate in creating the new system for Scotland.

“I think the fact SG is asking for those with lived experience to be involved is a huge step forward for the people of Scotland. That matters. Each interaction (in groups, one to one, over the phone or by email) has reminded me this is being taken seriously and will make a real difference, that's been reflected in the manner I have been spoken to, treated etc by all involved. I think using multiple methods of gathering info is also worthwhile and means more opportunities to be included!”

“It feels as though someone is finally listening to us!”

“The people that I met have been very sympathetic to my mental illness and are very supportive while I was talking about my illness.”

Choice of how to take part

Panel members felt that being offered the choice about how to participate was helpful.

“Giving us choices about participating, different formats and enough time to complete [surveys]”

In particular, some panel members commented that this was helpful in allowing them to take part in a way that works for them, depending on their disability or health condition.

“Allowing all users the opportunity to feel part of the process and make some contribution within the limit of their abilities.”

Some also commented that they felt that the options available were accessible for people with different disabilities and health conditions, as well as people with caring responsibilities. Having choices of how to take part were an important part of this.

“The accessibility of the panels is very good, provision of information is good and it is easy to contact people if help is needed.”

Some commented that it works well that panel members can participate as much or as little as they choose to without it impacting on opportunities to take part.

“Being kept on the membership list of the Experience Panel, despite having minimum contact (the issues continue, and always will continue, to be important). It is very good that you continue to seek input from all who have shown an interest, to any extent, in shaping the new system.”

Option to take part online, by phone or on paper

A number of respondents felt that the opportunity to complete surveys either online or by phone or post was working well. Reasons included that questions are clear and easy to understand, and that surveys include the opportunity to include more information with your response and are not just tick-boxes. Some commented that the survey format was easy to use.

“I think the various surveys have been designed very well and have been made accessible for everyone.”

“The colours you use on the survey screens is excellent - Thank you”

“One of the things I've particularly liked is that the questions asked tend to go into quite a bit of depth, and often allow for more open-ended responses than many other surveys and questionnaires do. It's often difficult to capture an answer around issues like these in a simple 'tick one of the following boxes' way, so being able to elaborate on my thoughts and explain the nuances has been a rare treat.”

Option to attend face-to-face events

Many respondents described positive experiences of attending panel events or focus groups. Respondents felt that having small groups worked, that they felt listened to, and that sessions have been easy to take part in. Some commented on the value of local venues – particularly hosting sessions in Inverness for people who live further north in Scotland. Others commented that they enjoyed the opportunity to meet people who had had similar experiences to them. A number of respondents commented that staff were friendly and helpful.

“The format for discussion worked well because the size of the group wasn't too large (we were split into two groups) and there was a relaxed atmosphere in comfortable surroundings. I believe the format is a successful one and facilitates productive discussion. It felt as if we had genuinely achieved something.”

What can we improve?

We asked panel members to tell us about how we can improve taking part in the Experience Panels. Key themes in response to this included having more events in different parts of Scotland and offering more events overall, and offering more opportunities to take part in other ways – for example online or through paper surveys. Some commented that having more choice on timings for events would be beneficial for them or made suggestions on how the experience of attending face to face sessions could be improved. Others felt that they would like to receive more information or updates on the research and progress in implementing the new system.

“The format has been easy to take part in, staff are very friendly and happy to help.”

“Meeting different people and learning what they have gone through and their struggles”

We have outlined the steps we are taking to respond to this feedback in the “next steps” section of this report.

More opportunities for face-to-face events in your local area

One of the key areas that panel members felt would improve their experience was holding more events in their local areas.

“More touring to all areas of Scotland”

“More sessions [in] the more remote areas of Scotland, rather than concentrating on the big cities, travel out to the smaller communities as our issues can be very different to those in the large cities.”

Others suggested that having technology options that would allow people to participate remotely (for example through video conference or Skype) may be helpful to allow some people who live in remote areas, or who cannot easily attend events, to take part in discussions.

Some suggested that offering the opportunity to have a home visit with a researcher would help them to participate better.

“My husband has severe anxiety but would like to participate, so some home-based visits would have been a better option or it risks excluding people who for whatever reason cannot get to external venues.”

Some panel members also felt that it would be beneficial to run more events overall, or had faced barriers getting spaces on events due to them being oversubscribed.

“Make more spaces available or ensuring it is not the same few people that attend these meetings (there was no room for me to attend)”

Other options for participating

Respondents also suggested that more options should be available for people to contribute if they are unable to attend face-to-face events. Suggestions included offering surveys looking at the same topics being addressed in focus groups and that this could benefit people who cannot attend for a range of reasons including

location, their disability or health condition, caring responsibilities, or because an event is sold out.

“Could more be done online or by phone to reach people unable to attend venues?”

“People who cannot take part by attending events should be able to take part in other ways i.e. online”

Timing of events

Another key area relating to face-to-face events related to the timing of events. Some panel members said that events held during working hours would not be an option for them due to work or other commitments. Others felt that the time offered didn't suit them for other reasons – for example an afternoon slot would have worked better than a morning slot due to the nature of their condition. Some felt that it would be beneficial to offer multiple time slots, or multiple choices of dates for events.

“I've been unable to take part in any of the focus groups as I work during the day. It would be good if a few could be run in the evening for those of us who are unable to attend during the day as you are missing out on a large section of claimants.”

Ways to improve the experience of attending events

Some panel members felt that some venues used could have been more accessible – in particular having access to changing facilities, better parking and transport links.

Panel members also described a number of other areas where face to face events could be improved. This included giving panel members more advanced notice of the dates of events, and providing more detailed information about the venue – for example accessibility information and how to get there.

“Be more informative also more updates on all aspects; more opportunities for stakeholders to have their input”

“In the latest information about focus groups and interviews you made it clear that I would be able to bring someone with me for support. Please keep doing this.”

In terms of the content of sessions, a small number of panel members felt that the format of face-to-face sessions was too simple, that too much time was spent on research consent forms, or had found other participants disruptive.

Provide more information or updates on the research and new system

A number of respondents felt that it would be helpful to have more information shared with them, in particular updates on the process of transferring the benefits to Scotland and feedback on their contribution to the research.

Closer ties and more regular feedback, otherwise people become disillusioned and feel that their contributions are irrelevant.

Some participants felt that it is taking too long for the new system to be implemented.

Taking part is fine but all this is taking a long time. I'm sure I'm not alone in wishing the system was already up and running. The current system is killing people. Scotland needs to move as quickly as possible.

Next steps

Widening Engagement

Experience Panels consists of a diverse range of people from different backgrounds and with a wide range of experiences. However, we are conscious that there are a number of groups of people who are underrepresented in the panel, or who may find it difficult to engage with the Experience Panels format.

Ethnic Minorities

We have long recognised the importance of ensuring minority ethnic voices are heard in the Experience Panels work. We have addressed this in two ways to date. In benefit specific design work to date where few minority ethnic panel members have volunteered to take part, we have recruited minority ethnic users separately from Experience Panels to ensure there is no gap in the composition of participants in research at this early stage of the design process.

We have also run a series of three events to engage with minority ethnic people in Aberdeen, Kilmarnock and Glasgow, with a focus on those with English as a second language. So far we have engaged with around 120 minority ethnic people through this channel, many of whom have no direct experience of the benefits being devolved, because of the barriers they face.

We will now review the findings from those events and design further events with wider age groups and across the country. We will retain the dual purpose of

conducting standalone research events, and using these to recruit participants as panel members. This will run alongside specific targeting of ethnic minorities when we reopen recruitment to experience panels later in the year, in partnership with relevant stakeholder organisations.

Young People

We have convened a standalone panel of young carers to support design of Young Carer's Grant. However, we know that young people are also recipients of other of the benefits being devolved, and will target this group when we reopen recruitment.

Other groups

Building on the analysis in this report, we will use these findings to explore any gaps in representation among panel members who have participated in research to date. Any further gaps will be explored at that point.

We are also planning a project to engage with a range of marginalised, sensitive and dispersed groups who are either difficult to identify among panel members, have quite different experiences or require particular sensitivity. We are in the process of scoping out which groups this work should include, but broad categories covered by this work are likely to be mobile populations, vulnerable groups, survivors and carers, and bereaved people/those with terminal illnesses. Research with all of these groups will run parallel to the wider Experience Panels over the coming years, feeding into design decisions in the same way.

Improving panel member experience

Location of events

We are working hard to ensure that events are held in different locations across Scotland. At least once per year we carry out a programme of events which are run in different locations across the country to hear from a wide range of perspectives.

We additionally try to ensure that smaller pieces of work, focussing on individual benefits or parts of the system, are not just held in the central belt. This is whilst also recognising that the a large number of the panel are located in Edinburgh and Glasgow and so holding events in these locations is also important.

We will continue to work hard to ensure that events are held in accessible venues with good transport links and will provide information to panel members about the venues.

We are currently agreeing a process through which we will be able to offer home visits to panel members, and this option will soon be available to those who need it.

Options on how to take part

Experience Panel members are always asked to let us know if they are unable to attend face-to-face events due to accessibility barriers. Where possible, we have

offered to try to find solutions to these barriers, or to find alternative ways of contributing, for example through a phone interview or in writing.

For surveys, panel members are always offered the opportunity to take part online, by post, or by phone.

Where possible, in almost all of our projects that involve face-to-face events, we also offer a survey option or option to take part over the phone. We will continue to offer this and to invite panel members to let us know if there are other steps we can take to make it easier for them to take part in research activity.

Subscribing to events

At the outset to the Experience Panels project, all panel events were advertised on a first come, first served basis. However, a number of events proved highly popular and we found that events were selling out within a very short period of time – sometimes within half an hour of issuing an invitation. We received feedback that this was a barrier to anyone who could not regularly check their emails or post, for example people with caring responsibilities and people who suffer from a number of different health conditions.

We therefore have recently trialled an approach where panel members can register interest in attending an event, and then attendees are selected by random ballot. We have aimed to prioritise those who have not been selected for previous events on that topic. Feedback on this approach has been positive from many panel members who feel that it is fairer and avoids them worrying if they don't see an email straight away, however a few felt that the first come first served system was easier and fairer.

Providing more information and feedback

We are currently in the process of analysing the surveys and focus groups from the research carried out during the spring and summer of 2018. We will publish these reports over the coming months in a format that is simple and accessible to panel members.

We are also currently looking at options about how to better communicate regular updates to the Experience Panels about the decisions that are being made and changes that are coming. This will include feedback events and a regular Experience Panels newsletter.

Conclusion

This survey has provided invaluable data about panel members and their experiences. As well as using this as a basis for the work outlined above, we will rerun this survey on an annual basis to help us continuously improve across the lifetime of the Experience Panels project.

How to access background or source data

The data collected for this 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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