Social Security Experience Panels: Who is in the Panels? - 2020 Update - Full report

EQUALITY, POVERTY AND SOCIAL SECURITY

social research

Introduction

The Scottish Government is becoming responsible for some of the benefits previously delivered by the Department for Work and Pensions (DWP). As part of work to prepare for this change, Scottish Government set up the Social Security Experience Panels with people who have experience of one or more of the relevant benefits.

More than 2,400 people registered as panel members when we launched in 2017. The Scottish Government works with panel members to inform key decisions in the design of social security in Scotland.

This is the second '*Who is in the panels?'* report produced for the Experience Panels programme of research.[1] Since the last *'Who is in the panels?'* publication in October 2018, the Experience Panels team has completed a recruitment campaign for new panel members.[2] Between July 2019 to March 2020, we publicised the panels and encouraged people with experience of the benefits coming to Scotland to join and take part in our research. 572 people with experience of the benefits system joined as new Experience Panel members.

This report has three purposes. First, it sets out the demographic and benefit experience information available for the new panel members who have recently joined the Experience Panels between July 2019 and March 2020. Secondly, it also provides an up-to-date summary of the demographic information available for the entire Experience Panels membership. This now includes both panel members who joined us in 2017, and panel members who have joined recently in 2019 or 2020. Thirdly, the report also includes a brief section on feedback. In this section, panel members provide their feedback on taking part in the Experience Panels research, and offer suggestions for how the Experience Panels programme could be improved.

Throughout the report, we combine information collected through a number of '*About You'* suveys and *'Registration Forms'* that panel members have responded to (see Methodology section). We provide information on the Experience Panels' membership by age, gender, religion and belief, sexual orientation and gender

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[1] The first *'Who is in the panels?'* report was published in October 2018. Link: https://www.gov.scot/publications/social-security-experience-panels-panels-experiences-far/

[2] Recruitment for new panel members was re-opened in July 2019 to top-up panel membership. This was to ensure that the Experience Panels programme of research has enough panel members to obtain high levels of participation in its research. At the same time, recruitment was also re-opened with the aim of recruiting several groups which were unrepresented within the existing membership. These unrepresented groups that were identified included young people, ethnic minorities, and those living in island communities.

identity. Information is also provided for panel members by disability and long term health conditions, caring responsbilities, experience of different benefits, along with comparisons of how panel members are spread between urban and rural locations in Scotland. No panel member is personally identifiable throughout the report.

We will continue to re-run our '*About You*' surveys regularly with the aim of increasing the proportion of panel members we have demographic information on.

Summary

New panel members

Between July 2019 and March 2020, the Experience Panels team completed a campaign to recruit new panel members. This was done to top-up the overall panel membership which had fallen, as well as to recruit panel members from groups which were unrepresented in the existing membership. 572 new panel members with experience of the benefits system joined the Experience Panels. Of those new panel members, up to 322 then provided detailed demographic information through either the *'About You 2020'* survey or the *'About You YCP'* survey.

Of those new panel members:

- 73 per cent of respondents identified as "woman/girl", and 25 per cent identified as "man/boy."

- 3 per cent of respondents said that they were aged between 16 and 24. 27 per cent said were aged between 25 and 44. 46 per cent said they were aged between 45 and 59, and 24 per cent said they were aged over 60.

- 97 per cent of respondents describe their ethnic group as "white," and 3 per cent said they were part of a non-white minority ethnic group.

- 54 per cent of respondents said that they had no religion. 15 per cent said that they were Church of Scotland, and 13 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.

- 85 per cent of respondents identified as heterosexual or straight. 9 per cent identified as lesbian, gay or bisexual and 2 per cent identified in another way. Less than 10 respondents identified as transgender.

- 79 per cent of respondents said that they had at least one disability or long-term health condition.

- 61 per cent of respondents said that they look after or give regular support to someone who has either a long term physical condition, mental ill-health, disability, or problems relating to old age.

- 72 per cent of respondents said that they had experience of Personal Independence Payments (PIP). 33 per cent said that they had experience of Carer's Allowance, and 8 per cent had experience of Best Start Grant.

551 new panel members completed the '*Experience Panels* '*Registration Form'* and provided their postcode. In these responses:

- Postcodes in all 32 local authority areas in Scotland were provided. These included 11 per cent of respondents who live in City of Edinburgh, 9 per cent who live in Glasgow City, and 8 per cent who live in Fife.

- 70 per cent live in either 'Large Urban Areas' or 'Other Urban Areas.' 20 per live in either 'Accessible Rural Areas' or in 'Remote Rural Areas.'[3]

All panel members

We combined the available responses from all of the *'About You'* surveys that have been asked between 2017 and 2020.[4] The information available for the **entire Experience Panel membership** is as follows:

- 65 per cent of respondents identify as "female" or as a "woman or girl," and 33 per cent as "male" or as a "man/boy".

- 1 per cent of respondents said that they were aged between 16 and 24. 23 per cent said were aged between 25 and 44. 47 per cent said they were aged between 45 and 59, and 27 per cent said they were aged over 60.

- 97 per cent of respondents describe their ethnic group as "white," and 2 per cent said they were part of a minority ethnic group.

- 52 per cent of respondents said that they had no religion. 15 per cent said that they were Church of Scotland, and 12 per cent said they were Roman

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[3] The Scottish Government Urban Rural Classification uses categories such as 'Large Urban Area' and 'Remote Rural Area' to provide a consistent way of defining urban and rural areas across Scotland. The classification is based upon criteria defined by the National Records of Scotland. For more, see: https://www.gov.scot/publications/scottish-government-urban-rural-classification-2016/pages/2/

[4] Most demographic information for panel members was collected through six surveys – (1) *'About You 2017',* (2) *'About You 2018',* (3) *'About You 2019a',* (4) *'About You 2019b',* (5) *'About You 2020',* and (6) *'About You YCP.'* Only postcode data, which was used to produce comparisons of how panel members were scattered geographically, was collected separately - through the *'Experience Panels Registration Form.'*

Catholic. A number of other religions were represented among respondents, ranging from 1 to 3 per cent of respondents.

- 85 per cent of respondents identified as heterosexual or straight. 9 per cent identified as lesbian, gay or bisexual and 2 per cent identified in another way. 1 per cent of respondents identified as transgender.

- 82 per cent of respondents said that they had at least one disability or long-term health conditions.

- 52 per cent of respondents said that they look after or give regular support to someone who has either a long term physical condition, mental ill-health, disability, or problems relating to old age.

- 61 per cent of respondents said that they had experience of Disability Living Allowance (DLA). 70 per cent said they had experience of Personal Independence Payments (PIP). 37 per cent said that they had experience of Carer's Allowance.

2,193 panel members completed the '*Experience Panels 'Registration Form'* and provided their postcode. In these responses:

- Postcodes in all 32 local authority areas in Scotland were provided. These included 13 per cent of respondents who live in Glasgow City, 12 per cent who live in City of Edinburgh, and 7 per cent who live in Fife.

- 72 per cent live in either 'Large Urban Areas' or 'Other Urban Areas.' 16 per cent live in either 'Accessible Rural Areas' or in 'Remote Rural Areas.'

Feedback – what has worked well?

There were a range of thoughts from respondents about what had worked well when they had taken part in the Experience Panels. The most common view from respondents was that they valued that their voice was being listened to and was being used to shape decisions.

Others described the positive impact of meeting other panel members who had similar experiences during Panel events. These respondents felt that meeting other people gave them a chance to listen, learn, and sometimes be challenged.

Many also commented on the variety of research opportunities that were available. There was positive feedback for quick surveys – particularly online surveys.

A number of respondents also felt that communication between panel members and the Experience Panels team had worked well. This included the clear language

used as well as the frequency of contact with panel members. Many were also positive about the way that they had been treated by the Experience Panels staff at research events.

Feedback – what could be improved?

A number of respondents had thoughts on how events could be improved. Some described different reasons why they had been unable to attend events. These included being unable to travel long distances to events due to limited travel options, caring and childcare responsibilities, work commitments, or a health condition. Several respondents suggested streaming Experience Panels events via video-link, so that those who couldn't attend physically, could still tune in and take part.

There were also comments about how to improve the specific research approaches of Experience Panels. A couple of respondents described small changes to the format of surveys. Several respondents also had thoughts on how focus group formats could be improved. These included keeping the groups small and working to ensure that all voices in a focus group were heard equally. Several respondents asked if panel members could be given more time to prepare for focus groups.

Other respondents expressed concern about being over-consulted on very small decisions. Several said they would like it if the Experience Panels team told them about wider job opportunities in Social Security Scotland.

Methodology

Between 2017 and 2020, the Experience Panels team has invited panel members to participate in surveys to help us understand more about who is in the Panels. Firstly, a panel member provides some initial information on their *'Registration Form.'* We then invite registered panel members to tell us a bit more about themselves through an '*About You'* survey.

Our '*About You'* surveys collect demographic data of panel members who choose to respond. Respondents provide information such as age, gender, ethnicity, religion and belief, sexual orientation and gender identity. '*About You'* surveys also ask panel members about their benefits experience, caring responsibilities, along with any diasbilities and long-term health conditions they wish to disclose. Some

surveys have also asked questions to allow panel members to provide feedback, and help us ensure that they have a positive experience whilst taking part in our research.

The full list of '*About You*' surveys, launched by the Experience Panels team between 2017 and March 2020, is as follows:

Survey title	Survey detail	Date range (month)	No. of responses combined into this analysis
'About You 2017'	Asked the first Experience Panel members to provide their demographic information and their benefit experience.	Mar 2017 – Sept 2017	1064
'About You 2018'	Asked existing panel members to update their details. It also asked additional questions that were not included in the earlier 'About You 2017' survey on demographic characteristics (such as ethnicity, faith, and sexual orientation). It also asked for feedback on existing Experience Panels research.	May 2018 – Nov 2018	403
'About You 2019a'	Asked existing panel members to update their demographic information, their benefit experience, and provide some feedback on existing Experience Panels research.	Oct 2019 – Mar 2020	331
'About You 2019b'	Single-question survey asked existing panel members to re-answer one demographic question in 'About You 2019a' after it was asked incorrectly.	Nov 2019	375
'About You 2020'	Asked all new panel members, who joined the Experience Panels between July 2019 and March 2020, to provide demographic information and their benefit experience.	Jul 2019 – Mar 2020	320
'About You YCP'	Asked members of the Young Carer Panel (YCP), who had indicated that they wished to join the main Experience Panels, to provide their demographic information and their benefit experience.	Nov 2019 – Dec 2019	<10

Each '*About You*' survey received a different number of responses from panel members. These responses were combined into this report's analysis. Some '*About You*' surveys were sent to all existing panel members as ways to keep their details updated – e.g. '*About You 2019a.*' Other '*About You*' surveys were targetted at particular panel members – e.g. '*About You 2020*' was sent only to those who had joined the panels in the recruitment campaign between July 2019 and March 2020.

All questions asked in '*About You*' surveys are optional. Early '*About You*' surveys contained a smaller set of questions than later ones.[5] Responses were collected as paper submissions, online, or through a phone call. Accessible formats of '*About You*' surveys were available on request.

In order to complete the analysis, the available data from across six individual '*About You*' surveys were first cleaned. This included removing panel members who had responded to an '*About You*', but were no longer 'active.'[6] Scottish Government reseachers then combined all available data from the responses of 'active' panel member's into one secure master dataset. All personal identifiable information was stored in a separate secure file.

As part of the process of combining responses into a master dateset, responses in surveys were matched with individual panel member accounts. This was done to ensure that no responses were double counted. Where panel members had submitted responses to multiple '*About You*' surveys over time, in most cases the analysis was structured to account for their most recent response. This was done to make sure that responses that may change over time were captured – e.g. age.[7]

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[5] Some demographic questions (on ethnicity, religion and belief, sexual orientation and gender identity) were asked for the first time in the '*About You 2018*' survey. These questions were removed from the '*About You 2017*' survey at the user testing stage. This was because panel members told us they were not comfortable sharing this information at that stage. Once trust had been built up with panel members after the first year of the Experience Panels, we added those questions to the 2018 survey, and have asked those in subsequent '*About You*' surveys.

[6] The Experience Panels team monitors panel membership to ensure that panel members are 'active' – i.e. that they are receiving invites to new research and are happy to continue taking part. If a panel member has not been in touch recently, we will make contact to ensure their details are accurate. Panel members who are continually unresponsive may have their membership 'frozen.' Equally, panel members can be 'frozen' if they choose to take a break from the Panels. Panel members can also choose to leave the Experience Panels at any time.

[7] Due to a matching error in the '*About You 2018,*' survey, it was not possible to collate up to 622 responses into this analysis; however these responses were included in the 2018 analysis. The report is available at: https://www.gov.scot/publications/social-security-experience-panels-panels-experiences-far/

Once the data had been cleaned and accurately matched, it was then anaylsed. Analysis was split into two parts:

- Analysis of the data available for **new** panel members, who joined the Experience Panels between July 2019 and March 2020, following our most recent recruitment campaign.

- Analysis of the data available for the **entire** Experience panel membership.

Throughout the report, no panel member is personally identifiable. To protect the anonymity of respondents, we have not published low values (i.e. less than 10) in the tables presented in the sections below.

The information provided in this report must be understood as being representative of these respondents only and not of a wider population.

Age and Gender

New panel members

We asked new panel members about their age and gender. [8] 320 people responded to this question.

73 per cent of these respondents identified as a "woman/ girl", 25 per cent as a "man/boy".

When asked about their gender, 1 per cent of respondents said that they identified in another way. However, more detailed breakdowns of this group cannot be published to avoid the possibilty of individuals being identified.

One per cent of these respondents preferred not to say their gender. Due to the small number of people who responded this way, the breakdown of these groups by age are not included in the table below.

Three per cent said that they were aged between 16 and 24. 27 per cent said they were aged between 25 and 44. 46 per cent said they were aged between 45 and 59, and 24 per cent said they were aged over 60.

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[8] New panel members were asked about their age and gender in the '*About You 2020*' and '*About You YCP*' surveys.

Table 1: New panel members - respondents by age and gender (n=320)

	Woman / girl	% Woman / Girl	Man / boy	% Man / boy
16-24	<10	3%	<10	0%
25-44	71	22%	12	4%
45-59	108	34%	35	11%
60-79	44	14%	32	10%
80 or over	<10	0%	<10	0%
Total	**232**	**73%**	**81**	**25%**

All panel members

Across a number of different *'About You'* surveys, we have asked panel members about their age and gender. Responses from 1,530 panel members are available to be presented in Table 2.[9]

65 per cent of respondents identified as "female" or as a "woman/ girl", 33 per cent as "male" or as a "man/boy".

When asked about their gender, 1 per cent of respondents said that they identified in another way. However, more detailed breakdowns of this group cannot be published to avoid the possibilty of individuals being identified.

One per cent of these respondents preferred not to say their gender. 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 (73 per cent) of respondents were over the age of 45. A quarter (27 per cent) were over the age of 60.

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[9] Data on age and gender was collected and combined from five *'About You'* surveys (*'About You 2017', 'About You 2018', 'About You 2019a, 'About You 2020', 'About You YCP'*).

Table 2: All panel members - respondents by age and gender (n=1,530)

	Woman / girl	% Woman / girl	Man / boy	% Man / boy
15 or under	<10	0%	<10	0%
16-24	19	1%	<10	0%
25-44	263	17%	85	6%
45-59	472	31%	238	16%
60-79	235	15%	172	11%
80 or over	<10	0%	<10	0%
Total	**998**	**65%**	**509**	**33%**

Compared to available responses from the 2018 findings, panel membership by age and gender has stayed proportionately similar.[10]

Ethnicity

New panel members

We asked new panel members about their ethnicity.[11] 319 people responded in this question. As responses were low across a number of ethnic groups, these responses have been treated as "white ethnic groups", "non-white minority ethnic groups" and "prefer not to say."

97 per cent of respondents identified as 'White ethnic group", compared to 3 per cent identified as a 'non-white minority ethnic group.' One per cent of respondents preferred not to give their ethnicity.

[10] See the 2018 figures relating to panel members' age and gender in the original '*Who is in the Panels'* report https://www.gov.scot/publications/social-security-experience-panels-panels-experiences-far/

[11] New panel members were asked about their ethnicity in the '*About You 2020'* and '*About You YCP'* surveys.

Table 3: New panel members - respondents by ethnic group (n=319)

	Number of respondents	% respondents
White ethnic groups	309	97%
Non-white minority ethnic groups	<10	3%
Prefer not to say	<10	1%

All panel members

Across a number of different *'About You'* surveys, we have asked the Experience Panels' membership about their ethnicity. Responses from 925 panel members are available to be presented in Table 4.[12]

As responses were low across a number of ethnic groups, these responses have been categorised as "white ethnic groups", "non-white minority ethnic groups" and "prefer not to say."

97 per cent of respondents identified as a 'White ethnic group", compared to 2 per cent identified as a 'non-white minority ethic group.' One per cent of respondents preferred not to give their ethnicity.

Table 4: All panel members - respondents by ethnic group (n=925)

	Number of respondents	% respondents
White ethnic groups	895	97%
Non-white minority ethnic groups	22	2%
Prefer not to say	<10	1%

Compared to available responses from the 2018 findings, panel membership by ethnicity has stayed proportionately similar.

Additional research with ethnic minorities:

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[12] Data on ethnicity was collected and combined from five '*About You'* surveys (*'About You 2017, 'About You 2018', 'About You 2019a', 'About You 2020',* and *'About You YCP'*).

Given that ethnic minority groups are underrepresented in the Experience Panels, in 2018, a standalone research project with ethnic minorities in Scotland was created. Scottish Government researchers in partnership with Happy to Translate conducted 20 focus groups with over 130 participants from an ethnic minority background.[13]

Religion and Belief

New panel members

We asked new panel members about their religion and beliefs.[14] 317 people responded in this question.

54 per cent of respondents said that they had no religion. 15 per cent said that they were Church of Scotland, and 13 per cent said they were Roman Catholic. 5 per cent prefered not to say.

Table 5: New panel members – respondents by religion or belief group (n=317)

	Number of respondents	% respondents
None	170	54%
Church of Scotland	47	15%
Roman Catholic	40	13%
Other Christian	26	8%
Muslim	<10	1%
Pagan	<10	1%
Another religion or belief group	12	4%
Prefer not to say	16	5%

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[13] The main report and visual summary is available on the Experience Panels publications page: https://www.gov.scot/collections/social-security-experience-panels-publications/

[14] New panel members were asked about their religion and beliefs in the '*About You 2020*' and '*About You YCP*' surveys.

All panel members

Across a number of different *'About You'* surveys we have asked Experience Panel members about their religion and beliefs. Responses from 923 panel members are available to be presented in Table 6.[15]

52 per cent of respondents said that they had no religion. 15 per cent said that they were Church of Scotland, and 12 per cent said they were Roman Catholic. 3 per cent prefered not to say.

Table 6: All panel members – respondents by religion or belief group (n=923)

	Number of respondents	% respondents
None	484	52%
Church of Scotland	140	15%
Roman Catholic	114	12%
Other Christian	85	9%
Pagan	25	3%
Muslim	<10	1%
Buddhist	<10	1%
Jewish	<10	0%
Another religion or belief group	29	3%
Prefer not to say	29	3%

Compared to available responses from the 2018 findings, panel membership by religion and belief has stayed proportionately similar.

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[15] Data on religion and belief was collected and combined from five *'About You'* surveys (*'About You 2017', 'About You 2018'*, *'About You 2019a, 'About You 2020', 'About You YCP*).

Sexual orientation and gender identity

New panel members

We asked new panel members about their sexual orientation and gender identity. 319 people responded in this question.[16]

85 per cent of respondents identified as 'heterosexual or straight.' 9 per cent identified as 'gay, lesbian' or 'bisexual' and 2 per cent identified in another way. One per cent did not answer the question. 4 per cent preferred not to say.

Table 7: New panel members - respondents by sexual orientation (n=319)

	Number of respondents	% respondents
Heterosexual/ straight	271	85%
Bisexual	15	5%
Gay/ lesbian	13	4%
Identify in another way	.<10	2%
Prefer not to say	12	4%

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

All panel members

Across a number of different *'About You'* surveys we have asked Experience Panel members about about their sexual orientation and gender identity.[17] Responses from 930 panel members are available to be presented in Table 8.

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[16] New panel members were asked about their sexual orientation and gender identity in the '*About You 2020'* and '*About You YCP'* surveys.

[17] Data on sexual orientation and gender identity was collected and combined from four '*About You'* surveys ('*About You 2018', 'About You 2019a', 'About You 2020', 'About You YCP*).

85 per cent of respondents identified as heterosexual or straight. 9 per cent identified as lesbian, gay or bisexual and two per cent identified in another way. 4 per cent preferred not to say.

Table 8: All panel members - respondents by sexual orientation (n=930)

	Number of respondents	% respondents
Heterosexual/ straight	794	85%
Gay/ lesbian	42	5%
Bisexual	40	4%
Identify in another way	19	2%
Prefer not to say	36	4%

97 per cent of respondents said that they do not identify as transgender. 1 per cent said that they do, and 2 per cent said that they would prefer not to say.

Compared to available responses from the 2018 findings, panel membership by sexual orientation and gender identity has stayed proportionately similar.

Disability and other long-term health conditions

New panel members

Questions on diasbility and long term health conditions were asked to new panel members. 322 people responded in this question.[18]

41 per cent of respondents said they have a physical disability, compared to 43 per cent who said that they suffer from chronic pain, and 55 per cent who said that they had another long term condition. 22 per cent said that they have a mental health condition.

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[18] New panel members were asked about any disabilities and long term health conditions in the 'About You 2020' and 'About You YCP' surveys.

Table 9: New panel members - respondents by disability or long term health condition (n=322)

	Number of respondents	% respondents
A physical disability	133	41%
Chronic pain lasting at least 3 months	140	43%
Another long-term condition	177	55%
Mental health condition	72	22%
Deafness or severe hearing impairment	22	7%
Blindness or severe vision impairment	16	5%
A learning disability	24	7%

79 per cent of respondents said that they had at least one disability or long term health condition.

We also asked respondents about how their disability or health condition affects them (Table 10).

56 per cent of respondents said that their disability or health condition affects their mobility (for example, walking short distances or climbing stairs). 45 per cent of respondents said that disability or health condition affects their stamina or breathing or fatigue levels. 37 per cent said that their disability or health condition affects their dexterity (for example, lifting or carrying objects, using a keyboard).

Table 10: New panel members – impact of disability or long term health condition (n= 322)

	Number of respondents	% respondents
Mobility (for example walking short distances or climbing stairs	179	56%
Stamina or breathing or fatigue	144	45%

Dexterity (for example lifting or carrying objects, using a keyboard)	119	37%
Memory	116	36%
Learning or understanding or concentrating	109	34%
Socially or behaviourally (for example associated with Autism, attention deficit disorder or Asperger's syndrome)	53	16%
Hearing (for example deafness or partial hearing)	32	10%
Vision (for example blindness or partial sight)	30	9%
Another way	15	5%
None of the above	11	3%

All panel members

Across a number of different *'About You'* surveys we have asked Experience Panel members about disability and long term health conditions.[19] Responses available from 1,529 panel members who answered the question are presented in Table 11.

50 per cent of all respondents have said they have a physical disability. 51 per cent also said that they suffer from chronic pain, compared to 57 per cent who said that they had another long term condition. 33 per cent said that they have a mental health condition.

82 per cent of respondents said that they had at least one disability or long term health condition.

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[19] Data on disability and long term health conditions was collected and combined from six '*About You*' surveys ('*About You 2017', 'About You 2018', 'About You 2019a', "About You 2019b', 'About You 2020', 'About You YCP*').

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Table 11: All panel members - respondents by disability or long term health condition (n=1,529)

	Number of respondents	% respondents
A physical disability	765	50%
Chronic pain lasting at least 3 months	779	51%
Another long-term condition	875	57%
Mental health condition	506	33%
Deafness or severe hearing impairment	129	8%
Blindness or severe vision impairment	75	5%
A learning disability	101	7%

Compared to available responses from the 2018 findings, the levels of disability and long term health conditions reported by panel members stayed proportionately similar.

In our 'About You' surveys, we have also asked respondents about how their disability or health condition affects them. Responses from 864 panel members are available to be presented in Table 12.

67 per cent of respondents said that their disability or health condition affects their mobility (for example, walking short distances or climbing stairs). 54 per cent of respondents said that their disability or health condition affects their stamina or breathing or fatigue levels. 45 per cent said that their disability or health condition affects their dexterity (for example, lifting or carrying objects, using a keyboard).

Table 12: All panel members – impact of disability or long term health condition (n=864)

	Number of respondents	% respondents
Mobility (for example walking short distances or climbing stairs	577	67%
Stamina or breathing or fatigue	463	54%
Dexterity (for example lifting or carrying objects, using a keyboard)	389	45%

Memory	363	42%
Learning or understanding or concentrating	310	36%
Socially or behaviourally (for example associated with Autism, attention deficit disorder or Asperger's syndrome)	126	15%
Hearing (for example deafness or partial hearing)	109	13%
Vision (for example blindness or partial sight)	96	11%
Another way	61	7%
None of the above	29	3%

Compared to available responses from the 2018 findings, the proportions of panel members who said that they were affected in different ways by a disability or health condition stayed broadly similar. Among panel members that we hold information on about disability and health conditions, there was a slight descrease since 2018 in those saying their condition impacted their mobility, and those saying it affects their stamina or breathing or fatigue.

Caring responsibilities

New panel members

We asked new panel members about their caring responsibilities. 319 people responded in this question.[20]

61 per cent of respondents said that they look after or give regular support to someone who has either a long term physical condition, mental ill-health, disabilty, or problems relating to old age. 38 per cent of respondents said that they do not have any caring responsibilities. Of the remaining respondents, 2 per cent preferred not to say.

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[20] New panel members were asked about their caring responsibilities in the '*About You 2020*' and '*About You YCP*' surveys.

Of those who had caring responsibilities, 29 per cent said that they cared for a child or children with a long-term physical condition, mental ill-health, or a disability. 69 per cent cared for an adult or adults with a long-term physical condition, mental ill-health, or a disability. 24 per cent said that they cared for an adult or adults who need support due to old age.

All panel members

Across a number of different *'About You'* surveys we have asked Experience Panel members about their caring responsiblities.[21] The information presented in this section reflects the combined data available for the 1,539 panel members who responded across the surveys.

52 per cent of respondents said that they have caring responsibilities and 46 per cent said they do not. Two per cent of respondents stated that they prefered not to say.

Of those who had caring responsibilities 25 per cent said that they cared for a child or children with a long-term physical condition, mental ill-health, or a disability. 74 per cent cared for an adult or adults with a long-term physical condition, mental ill-health, or a disability, and 31 per cent cared for an adult or adults who need support due to old age.

Compared to available responses from the 2018 findings, panel membership by different caring responbilities has stayed proportionately similar.

Experience of benefits

New panel members

We asked new panel members about their experience of different benefits. 322 people responded in this question.[22]

Respondents include those who are currently, or have previously, applied, got, challenged or appealed a decision for one of the relevant benefits, including those

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[21] Data on caring responsibilities was collected and combined from five '*About You'* surveys ('*About You 2017', 'About You 2018', 'About You 2019a', 'About You 2020', 'About You YCP*').

[22] New panel members were asked about their experience of different benefits in the '*About You 2020'* and '*About You YCP'* surveys.

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 13: New panel members - respondents by benefit type (n=322)

Benefit	Number of respondents	% respondents
Disability Living Allowance	131	41%
Personal Independence Payments	231	72%
Carer's Allowance	107	33%
Winter Fuel Payments	81	25%
Cold Weather Payments	71	22%
Discretionary Housing Payments	44	14%
Attendance Allowance	42	13%
Universal Credit	58	18%
Severe Disablement Allowance	26	8%
Scottish Welfare Fund	38	12%
Funeral Expenses Allowance	14	4%
Sure Start Maternity Grant	10	3%
Carer's Allowance (Supplement)	68	22%
Best Start Grant	26	8%

All panel members

Across a number of different *'About You'* surveys we have asked the Experience Panels' membership about benefit experience.[23] Carers Allowance Supplement and Best Start Grant were added in later surveys, as these are new payments being

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[23] Data on experiences of different benefits was collected and combined from five *'About You'* surveys (*'About You 2017', 'About You 2018', 'About You 2019a', 'About You 2020', 'About You YCP'*).

delivered by Social Security Scotland which did not exist when the Experience Panels started in 2017.

Table 14: All panel members - respondents by benefit type (n=1,544, IIDB=1065, CAS=322, BSG=322)

Benefit	Number of respondents	% respondents
Disability Living Allowance	942	61%
Personal Independence Payments	1081	70%
Carers Allowance	578	37%
Winter Fuel Payments	481	31%
Cold Weather Payments	451	29%
Discretionary Housing Payments	339	22%
Attendance Allowance	274	18%
Universal Credit	309	20%
Severe Disablement Allowance	235	15%
Scottish Welfare Fund	255	16%
Funeral Expenses Allowance	124	8%
Sure Start Maternity Grant	104	7%
Industrial Injuries Disablement Benefit**	68	6%
Carer's Allowance Supplement*	68	4%
Best Start Grant*	26	2%

There were some differences in the levels of benefit experience reported in 2018 and 2020. Among panel members that we hold information on about benefit experience, there was a slight descrease since 2018 in those saying they had experience of Disability Living Allowance.

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Geography – Local Authority and Urban / Rural

New panel members

We asked new panel members to provide their postcode in their '*Experience Panel Member Registration Form.'* Of the 572 new panel members that were recruited, geographic information is available for 551 respondents who provided their postcode.

Respondents provided postcodes from all 32 local authority areas in Scotland. These included 11 per cent of respondents who live in City of Edinburgh, 9 per cent who live in Glasgow City, and 8 per cent who live in Fife.

Table 15: New panel members – respondents by local authority (n=551)

Local Authority	Number of respondents	% respondents
City of Edinburgh	62	11%
Glasgow City	51	9%
Fife	42	8%
South Lanarkshire	39	7%
North Lanarkshire	28	5%
North Ayrshire	27	5%
Highland	26	5%
Renfrewshire	25	5%
Scottish Borders	18	3%
Dundee City	17	3%
Dumfries and Galloway	16	3%
West Lothian	16	3%

Falkirk	15	3%
Perth and Kinross	15	3%
East Ayrshire	13	2%
Inverclyde	13	2%
East Renfrewshire	12	2%
Angus	12	2%
East Lothian	11	2%
Aberdeenshire	11	2%
Moray	10	2%
West Dunbartonshire	10	2%
Na h-Eileanan Siar	<10	2%
Midlothian	<10	1%
South Ayrshire	<10	1%
Aberdeen City	<10	1%
Stirling	<10	1%
Argyll and Bute	<10	1%
East Dunbartonshire	<10	1%
Clackmannanshire	<10	1%
Orkney Islands	<10	1%
Shetland Islands	<10	1%

70 per cent of new panel members live in either 'Large Urban Areas' or 'Other Urban Areas.' 12 per cent live in 'Accessible Rural Areas', and 8 per cent live in 'Remote Rural Areas.'[24]

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[24] The Scottish Government Urban Rural Classification uses categories such as 'Large Urban Area' and 'Remote Rural Area' to provide a consistent way of defining urban and rural areas across Scotland. The classification is based upon criteria defined by the National Records of Scotland (NRS). For more, see: https://www.gov.scot/publications/scottish-government-urban-rural-classification-2016/pages/2/

Table 16: New panel members – respondents by area type (n=551)

Area type	Number of respondents	% respondents
Large Urban Areas	186	34%
Other Urban Areas	198	36%
Accessible Small Towns	40	7%
Remote Small Towns	19	3%
Accessible Rural Areas	65	12%
Remote Rural Areas	43	8%

All panel members

Across different *'Experience Panels Registration Forms',* we have asked panel members to provide their postcode. Responses were available from the 2,193 panel members.

Respondents provided postcodes from all 32 local authority areas in Scotland. These included 13 per cent of respondents who live in Glasgow City, 12 per cent who live in City of Edinburgh, and 7 per cent who live in Fife.

Table 17: New panel members – respondents by local authority (n=2,193)

Local Authority	Number of respondents	% respondents
Glasgow City	280	13%
City of Edinburgh	253	12%
Fife	157	7%
South Lanarkshire	138	6%
Highland	130	5%
North Lanarkshire	103	5%

Renfrewshire	92	4%
Dundee City	86	4%
North Ayrshire	71	5%
Perth and Kinross	68	3%
West Lothian	60	3%
Falkirk	60	3%
Scottish Borders	59	3%
Dumfries and Galloway	55	3%
West Dunbartonshire	50	2%
Angus	49	3%
Inverclyde	46	2%
Aberdeenshire	44	3%
East Renfrewshire	42	2%
Aberdeen City	42	2%
East Lothian	39	2%
Argyll and Bute	39	2%
East Ayrshire	36	2%
South Ayrshire	36	2%
Moray	34	2%
Stirling	33	2%
East Dunbartonshire	23	1%
Midlothian	22	1%
Clackmannanshire	18	1%
Na h-Eileanan Siar	13	1%
Orkney Islands	10	1%
Shetland Islands	<10	0%

72 per cent of panel members live in either 'Large Urban Areas' or 'Other Urban Areas.' 9 per cent live in 'Accessible Rural Areas', and 7 per cent live in 'Remote Rural Areas.'

Table 16: All panel members – respondents by area type (n=2,193)

Area type	Number of respondents	% respondents
Large Urban Areas	839	38%
Other Urban Areas	753	34%
Accessible Small Towns	165	8%
Remote Small Towns	83	4%
Accessible Rural Areas	200	9%
Remote Rural Areas	153	7%

Feedback on the Experience Panels

Respondents to *'About You 2019a'* were invited to provide feedback on their time as panel members. They were asked both what has worked well in relation to taking part in the Experience Panels, and what could be improved.

What has worked well?

There were a wide range of thoughts from respondents about what had worked well when they had taken part in the Experience Panels. Around two-thirds of survey respondents provided an answer about what had worked well.

Having a say

The most common view from respondents was that they valued that their voice was being listened to. Some said that they felt like, by taking part in research, they were having a direct impact in designing a system that they would soon be using. Others were pleased that they had the opportunity to explain their experiences and concerns fully.

"It has been really positive to feel that we are being heard, as the people who have first-hand experience of the system. It gives me hope that the inherent problems and mistakes in the current system will not be part of the new system."

"It's been good to have a say and put my points of view across. I feel my opinion has mattered and feel valued for contributing."

"For me, it has been the ability to explain things properly and hopefully having our voices heard and experiences listened to. Hopefully, this means that our new social security system will be a more emphathetic and accessible system, not like the hostile one that's currently in place."

Many respondents also described how they had appreciated being well-informed about both the work of the Experience Panels and ongoing design of Social Security Scotland.

"It's been good to be kept informed of your work and the outcomes of your research."

"Getting feedback which confirms the new set-up is going to be more user friendly and less confrontational is very reassuring."

Meeting other panel members

Several said that they had particularly liked meeting other panel members who had similar experiences during Panel events. These respondents felt that meeting other people gave them a chance to listen, learn, and sometimes be challenged.

"It's been amazing to be able to sound off and speak with others who have been treated badly."

"Meeting people involved either as staff or as participants has been stimulating. Hearing of other people's experience and how our views will be used to design good approaches is very satisfying."

"I've learnt a great deal from other Experience Panel members."

"I've enjoyed being in a setting where my views can change, being challenged by what others say."

Different types of research

Many also commented on the variety of research opportunities that were available. There was positive feedback for quick surveys – particularly online surveys. Many respondents felt that surveys were easy to access and complete. Several said that they liked that surveys gave them the chance to respond in their own time without any pressure. A few commented that online surveys worked well with any assistive technology that they used on their computer.

"The surveys have all been very well-designed, in particular by allowing me to give nuanced and in-depth responses to questions."

"I like the fact that I can choose which surveys I can take part in at my leisure and at my pace and hopefully my small part helps to shape a better and fairer system."

"Taking part in the online surveys has been a piece of cake! The format of the surveys has been easy to understand and to complete using voice recognition technology."

Some said they that struggled to get to events, and that surveys gave them an opportunity to input at a time that suited them.

"Online surveys are easiest for me. I work 32 hours a week over 4 days as well as being a carer for my husband, so attending events has proved difficult."

Others felt that face to face events and focus groups had worked well. These respondents enjoyed discussing their experiences with others and having a variety of discussions on different topics.

"Actually meeting face to face with interviewers has worked well."

Several respondents said they appreciated the flexibility of research opportunities and ways to communicate.

"I like the flexibility to participants in surveys or face to face sessions and other events depending on time availability."

<u>Communication and staff</u>

A number of respondents also felt that communication between panel members and the Experience Panels team had worked well. This included the clear language used as well as the frequency of contact with panel members.

"It's easy to respond. I've never felt under pressure to take part, and emails don't come too often."

"When I've asked questions, you've always responded promptly."

Many were also positive about the way that they had been treated by the Experience Panels staff at research events.

"The actual workers who have enabled this work to be done have been wonderful. They have listened and cared for everyone, changed things when suggested, and genuinely fostered confidence for the entire process. The ought to be commended for the things that might have been on the job description, but also for their authentic energy and positive regard for us all. Smiles in the right places and ways were most appreciated by me."

"Very friendly staff and very helpful. Good workshop style events, and allowing everyone to have their say during the event."

"I have enjoyed meeting the staff. I have felt heard and appreciated the level of fine attention given to everyone attending."

What could be improved?

When asked about what could be improved about the Experience Panels, respondents had a number of suggestions. Just under half of survey respondents provided a suggestion about how the Experience Panels could be improved. The remainder of respondents either did not provide an answer, or said that they could not think of improvements to be made.

<u>Events and venues</u>

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A number of respondents had thoughts on how events could be improved. Some described different reasons why they had been unable to attend events. These included being unable to travel long distances to the locations where events were being held. Travelling long distances was said to be difficult for those who lived in rural areas, had limited travel options, or had other responsibilities during the day such as childcare or work. Several respondents suggested that this had limited them to online participation only.

> "One thing is that it would be good to have more events round about Scotland – in Perth specifically. On my part, it can be very difficult, or in many cases impossible, to balance going further afield with my duties as a carer for my mum."

> "I appreciate there has been venues across Scotland to go to, but for individuals whom have physical disabilities and are unable to attend due to distance, it would be appreciated if possible to have venues within easier access. This would enable individuals to participate more. At present, I can only contribute online."

> "I'd ask for more morning workshops as my daughter is still at school and I can't do afternoons."

> "I can't always participate due to work."

Other respondents said that they were unable to attend events due to a health condition or a concern that attending would be too fatiguing.

> "I would like to be able to take part in workshops but owing to fatigue / health issues I doubt I would be able to. At least I can still do the surveys which is better than nothing."

> "It is very difficult for me to attend as there is a limit as to the length of time I can physically sit on a bus and waiting times for buses can be long."

There was also a view that event venues needed to be more carefully chosen in the future. Several respondents described having difficulties finding accessible on-site parking at venues. While others discussed the need to have suitable table arrangements for wheelchair users, along with clear-marked exits and toilets.

> "Maybe just a bit more room for wheelchair users in the meeting rooms – i.e. table positions."

> "Just getting the building suitable for easy wheelchair access and suitable disabled toilets. Also being clear as to how long the meetings take as I had to leave the last one early."

Several respondents suggested streaming Experience Panels events via video-link, so that those who couldn't attend physically, could still tune in and take part. There was also a suggestion for speakers to use microphones in busy events so that their voices could be clearly heard by all.

> "I have unfortunately not been able to attend any of the briefing sessions of focus groups. I can't imagine I'm alone in that and wonder if these events could be live streamed with the option of contributing by text."

> "Have speakers use a microphone and have two mics for audience members to use when asking questions. If this becomes normal, everyone will be able to hear!"

A number of respondents felt that it was a shame that some of the events that they had attended had not had a higher number of attendees. There were several suggestions to try and improve the attendance of panel members at events. This includes sending more reminders to panel members. There was also a suggestion that panel members could be given information about events earlier in advance.

> "Perhaps for individual panel days, more could be done to contact participants prior to the event? I have been to a couple of days where very few people actually attended."

> "Longer notice of when the focus groups are scheduled. The last one only gave about 10 days' notice for Glasgow. As I need to arrange for a driver for my vehicle, and for that person to help me access the venue, I need time to set up such arrangements. Notice of four weeks would be helpful."

Surveys and focus groups

There were also comments about how to improve the specific research approaches of Experience Panels. A couple of respondents described small changes to the format of surveys. They felt that it would be helpful to see a copy of the full survey before answering it, so that they could understand what questions were coming and how best to answer them.

> "For surveys – the current format does not allow me to see the questions in advance. I've often found that I've given a long answer only to find the next question addressed that better. Also you estimate that it will take 15 minutes to complete, but providing the number of questions would be better."

Several respondents also had thoughts on how focus group formats could be improved. These included keeping the groups small and working to ensure that all voices in a focus group were heard equally.

> "Smaller group sizes at the discussions with a maximum of 5 at a table to enable more discussion by the panel members. When the groups exceed this, the discussions become hampered by time restraints."

> "Sometimes only a few voices dominate the conversation. I think it is important that all participants are included in the conversations."

There was also a comment from several respondents that panel members could be given more time to prepare for focus groups. This included providing a clear indication of topics that were going to be discussed.

> "Provide an idea of topics 48 hours before meeting."

> "Perhaps a little more information on the subject under discussion beforehand. Sometimes I find it difficult to contribute from cold. I sometimes think of things after I've left and gone home which I'd have liked to contribute."

> "Perhaps being given some reading materials to allow for preparation before meetings and discussions."

Other thoughts

One respondent warned about being over-consulted about smaller details and how this could be overwhelming.

> "There is such a thing as consultation fatigue. I feel that we are being consulted constantly about every tiny item which we don't need to be consulted about. You can't agonise over the minutiae."

Several said that they would be interested in being alerted about wider job opportunities in Social Security Scotland.

"Email people involved in the panels with job opportunity within Social Security Scotland. We are all motivated and engaged people and nothing beats expertise from personal experience. I would love to work for the new social security system supporting people to apply and know their rights."

In addition, when asked about what could be improved about the Experience Panels, many did not provide any further suggestions. These respondents said that they were broadly content with the Experience Panels as they were.

What's next?

This report provides a valuable up-to-date picture about who is in the Experience Panels and what their experiences of taking part have been so far. It allows us to look at how the Panels are made up and how they have changed over time.

In addition, as the Experience Panels continues, the insights collected through our '*About You'* surveys allow us to continually evaluate our approach and make improvements. In particular, we will take feedback given on board to improve certain aspects of our approach. For example, for future research events, we will look into options to provide more information about research topics to panel members, so that they can prepare beforehand.

Soon we will re-run our '*About You'* survey and ask panel members to update their information again. In the meantime, 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
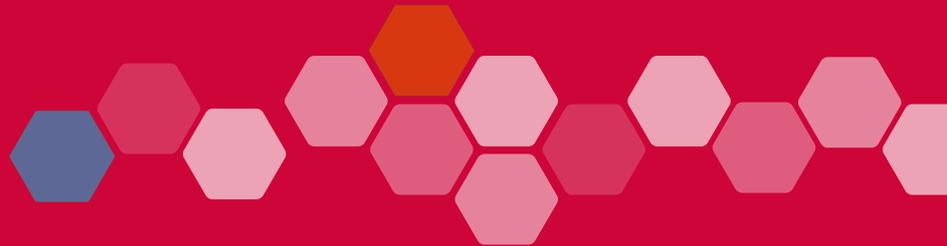
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