

## EQUALITY, POVERTY AND SOCIAL SECURITY

# Social Security Experience Panels: Seldom Heard Programme of Research: Carers and care experienced people

## Background

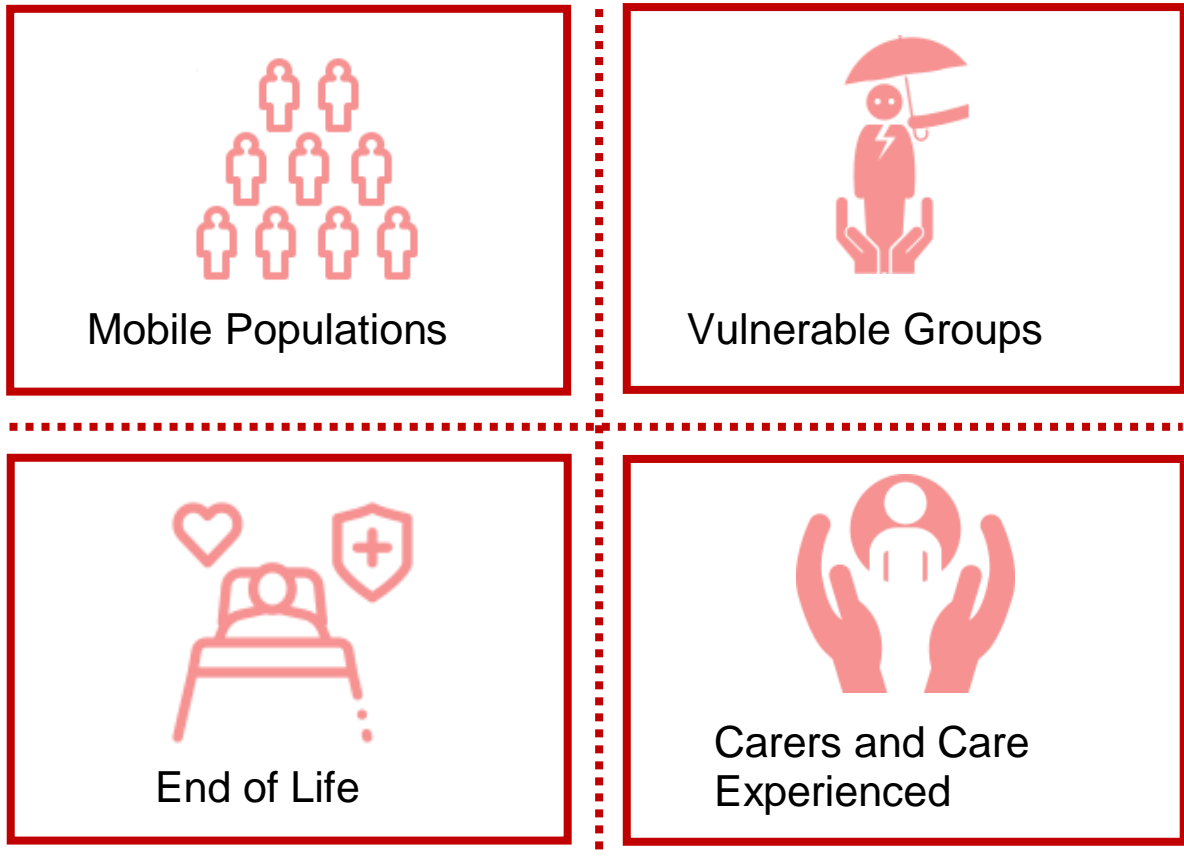


The Experience Panels were established in 2017 to help design a social security system that works for the people of Scotland. Members have experience of at least one of the benefits delivered by the Department for Work and Pensions (DWP) that has or will come to Scotland.



We recognised that there are groups less likely to be represented on the Experience Panels so we set up the “Seldom Heard Voices” research programme. It ensures that groups who need to be treated with particular sensitivity, are marginalised or dispersed have a voice in the design of Scotland’s social security services.

There are four groups which are identified as 'Seldom Heard' in this research programme. They are:

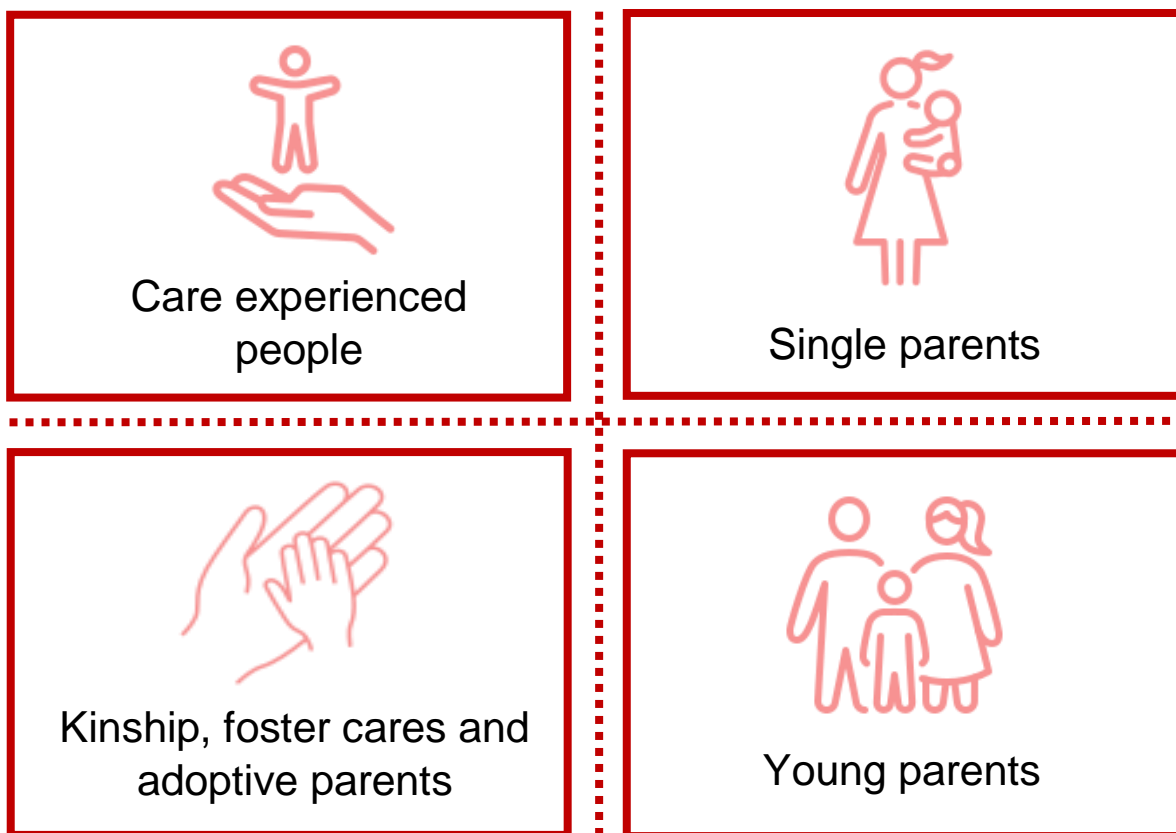


## About the research



For each of the four groups, two stages of research are being carried out. This summary sets out the findings from the first stage of research with Carers and Care Experienced people.

The Carers and Care experienced group includes the following:



The research included an online survey with 59 respondents, and focus groups and interviews with 95 research participants.



**16**

Individual interviews



**12**

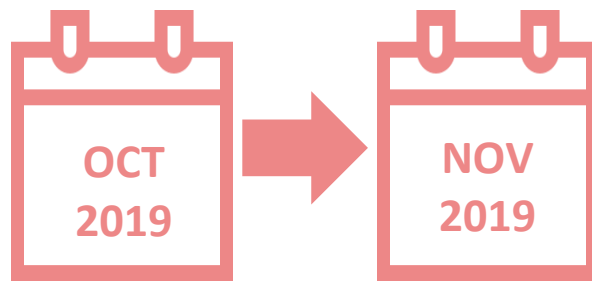
Focus groups



**59**

Survey responses


The research took place in



The research explored views on:




Finding out about benefits



Applying for benefits



Interacting with government agencies and organisations



Preferences for Scotland's Social Security system in the future

## About respondents of the online survey

Most participants (74%) were aged between

**17 – 44**

years old



**84%**

Female



**16%**

Male



**45%**

Just below half had a disability or long-term health condition



**27%**

Over one quarter said they were carers



**84%**

Most lived in an urban location



**16%**

Almost a fifth lived in a rural location



**7%**

were from an ethnic minority

# About participants of focus groups and interviews

Almost two thirds (63%) were aged between

**17 – 44**

years old



**86%**

Female

**14%**

Male



**22%**

Around one fifth had a disability or long-term health condition



**34%**

Around one third said they were carers



**92%**

Most lived in an urban location



**8%**

Almost a fifth lived in a rural location



**11%**

were from an ethnic minority

## Common barriers

Survey respondents and participants from all the carers and care experienced sub-groups experienced common barriers.



Many lacked knowledge of the benefit system and of entitlement for specific benefits. Some did not know where to find information.



Some highlighted difficulties with accessing information and application processes online because they did not have access to a computer or a smart phone. Others had no experience of using the internet. Some found government websites difficult to navigate.



Many felt stigmatised, judged and discriminated against by public sector staff, particularly when communicating with DWP and Job Centre Plus staff.



Some reported that the wording of the application forms was prescriptive, complex and long. The tick-box style questions did not allow them to convey the details and complexities of their particular circumstances.



Disability Living Allowance and Personal Independence Payment application forms were highlighted as the most complex and difficult forms.



Most who had health related assessments experienced embarrassment, anxiety and stress. They felt that there was an environment of suspicion and that the questions asked by assessors did not allow them to fully explain the details of some health conditions.



For some, long waiting times for award decisions and payments, changes to eligibility, interactions across benefits and overpayments led to a detrimental impact on household finances.

“The questions that were asked in my fit to work assessment really made my mental health a lot worse. But it’s not the questions, it’s the way they ask them. [...] And I’ve heard a lot of people say that, and it put me off going in the first place. And if I hadn’t been taken by my friend to go, I never would have gone and I never would have got the benefits because every time I set foot in the Job Centre Plus, I’ve felt very much like a number and very much beneath the staff.”

[Care experienced participant]





# Main challenges concerning specific groups

## Young parents



Young parents lacked awareness of benefits and had limited knowledge of application processes.



A few reported getting misinformation about benefits from official sources.



Some reported experiencing a lack of support when they reached out for help with benefits. They specifically mentioned this could be from Job Centre Plus staff.



“Like I can’t tell you how many times I have had to have an appointment and I have gone in [Job Centre] and they are like we don’t know why you are here, then I have gone away and then asked to come in again.”

[Young parent]

## Care experienced people



Some care experienced people, particularly those leaving care aged 16, reported having little knowledge and experience with the benefit system.



Others noted the difficulties of not being eligible for benefits until they are 18 years old.



Care experienced people found application processes difficult. Personal Independent Payment forms were frequently mentioned as the most difficult to complete.



Some relied on support from third sector organisations to complete forms.



The long waiting time between benefit application and payment created financial difficulties for many.



Some reported negative attitudes from DWP and Job Centre Plus staff. Many felt staff lacked empathy.

“I can’t even claim anything when I’m near enough turned 18. I’m expected to pay my own way, but I’ve no idea how the Government is expecting people to do it...The system is set up in a way that as soon as you turn 16, you’re classed as an adult and you can’t claim any sort of benefit until you turn 18. So, what are you meant to do for those two years? I don’t understand what it is you’re meant to do. Are those two years meant to be a survival challenge?”

[Care experienced participant]



## **Kinship, foster carers and adoptive parents**



Many kinship, foster carers and adoptive parents reported being unaware that they were entitled to benefits.



A few mentioned that biological parents were still claiming benefits for the children that were no longer in their care. Often they were unsure who was entitled to the benefit.



Collecting evidence for accessing some benefits acted as a barrier for some, as official documents required for a claim could be lost or still held by biological parents.



Many who cared for disabled children or a child with a long-term health condition experienced many problems with Personal Independent Payment, Disability Living Allowance and Carers Allowance applications. They found application forms complex and that assessments were not able to take chronic illnesses into account.



Some questioned the frequency of reassessments, especially when conditions were unlikely to change.



“...my son has chronic long-term conditions. They're not going to change. So, a two-year renewal process is just too short. I do get for some people, they might be in a short-term situation, but my son has complex needs and that's not going to change... it's the first time that I've claimed something, I found it really distressing and really, really challenging and I was quite shocked actually about how hard it is to get support.”

[kinship/foster carers and adoptive parent]

## Single parents



Single parents experienced delays in payments that led to financial difficulties. They frequently reported that this stemmed from a lack of information or misinformation from DWP and Job Centre Plus staff.



Many noted that third sector organisations were essential to them because of the lack of information and guidance from official channels.



Single parents experienced pressure because of having to look for work to access benefits, despite their caring responsibilities. This was detrimental to their mental health as they felt under suspicion from DWP and Job Centre Plus staff.



Many single parents who had experienced benefit changes, for example, being transferred from Income Support to Universal Credit, spoke of financial insecurity. They talked about experiencing debt, rent arrears, using foodbanks and getting payday loans.

“I applied for Universal Credit from ESA last year. It was a nightmare. Just getting paid, the time it took. There was no money available until six weeks or so after my claim. The only support I had was the foodbanks...They give you a loan [advance payment], because they know how your rent arrears will clock up in that space of time while you’re waiting for the money to get sorted. So they gave me a loan, and that loan had to be paid back every month at so much per month as well as deductions from Universal Credit as well, which left me just as bad as what it was before I started claiming in the first place. So it was a bit of a rigmarole.”

[Single parent]

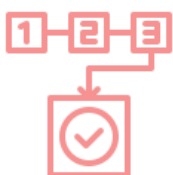


## Views on improving the benefit system

Survey respondents and participants from all the care and care experienced sub-groups provided suggestions on how to improve the benefit system.



Many suggested that having a range of choices to get information, apply for benefits and to find guidance would improve access to benefits.



Many stressed the need for information on eligibility criteria and for application processes to be consistent, clear and easy to understand.



Some suggested that application forms should be shorter, and that they should be designed with more flexibility so that clients can convey their specific circumstances.



Many highlighted the need for staff of benefit agencies to be appropriately trained in order to have a comprehensive understanding of benefits, and the interactions across benefits.



They also wanted interactions with benefit staff to be based on a respectful, compassionate and empathetic approach.



Some suggested that health assessments should be carried out by medical professionals who have an appropriate understanding of long-term physical and mental health conditions.



A few argued the frequency of assessments for clients should be reconsidered, especially for those who have long-term conditions which are unlikely to change.



Some suggested shortening waiting times between application and payment. Providing more flexibility to pay back overpayments, loans and advance payments could help clients to avoid financial difficulties.



Third sector organisations contributed to positive experiences with the benefit system. They are perceived as a good source of clear and comprehensive information.



“...but if you are in the situation where you have to apply for things, you need some compassion.”

“Compassionate people. People that aren’t going to mock you.”

[Single parents]

## Next Steps



The Scottish Government and Social Security Scotland will carry out (or has already carried out) actions to address the barriers, and views of improvement, that carers and care experienced people had.



Insights on access to information and knowledge of the benefit system has fed into the provision of inclusive communication approaches. Social Security Scotland provides transparent and accessible information. There are two [take-up strategies](#) that set out all the activity being undertaken to ensure awareness about benefits improves.





The design of Social Security Scotland benefit application forms has been developed with people experiencing the benefits.



Social Security Scotland offers a range of ways to apply for, and access support to the benefits they deliver. These include: online, telephone, paper-based or in person.



Social Security Scotland's [Charter](#) ensures that dignity, fairness and respect are embedded in the new system and in clients' interactions with staff.



Views on health assessments are being addressed by Social Security Scotland which will consider the use of supporting information from the medical profession.



The Scottish Government is working with stakeholders to develop an Overpayments Policy which has a key principle that no individual will be pushed into financial hardship as a result of repayment.



Insights on the key role third sector organisations play in supporting clients will inform engagement with these organisations. This will address barriers to benefit take-up and provide organisations with accurate information on benefits for their clients.



© Crown copyright 2022

You may re-use this information (excluding logos and images) free of charge in any format or medium, under the terms of the Open Government Licence.

To view this licence, visit <http://www.nationalarchives.gov.uk/doc/open-government-licence/> or e-mail: [psi@nationalarchives.gsi.gov.uk](mailto:psi@nationalarchives.gsi.gov.uk).

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

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

This report is available on the Scottish Government Publications Website (<http://www.gov.scot/Publications/Recent>)

The Scottish Government  
St Andrew's House  
Edinburgh  
EH1 3DG

ISBN: 978-1-80435-066-9

Published by the Scottish Government, February 2022