

**EQUALITY, POVERTY AND SOCIAL SECURITY**

# **Social Security Experience Panels - Seldom Heard Programme of Research: End of life**

## **Background**

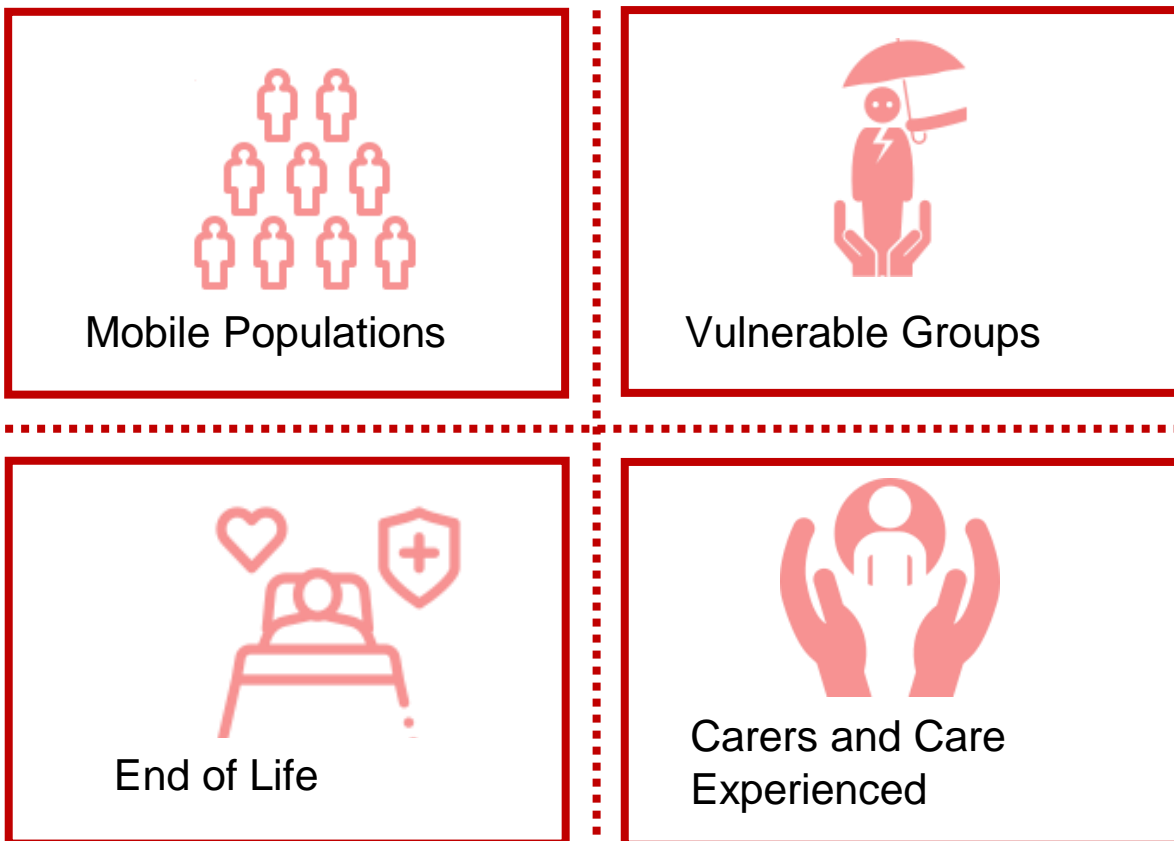


The Experience Panels were established in 2017 to help design a social security system that works for the people of Scotland. Members have experience of at least one of the benefits delivered by the Department for Work and Pensions (DWP) that has or will come to Scotland.



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:

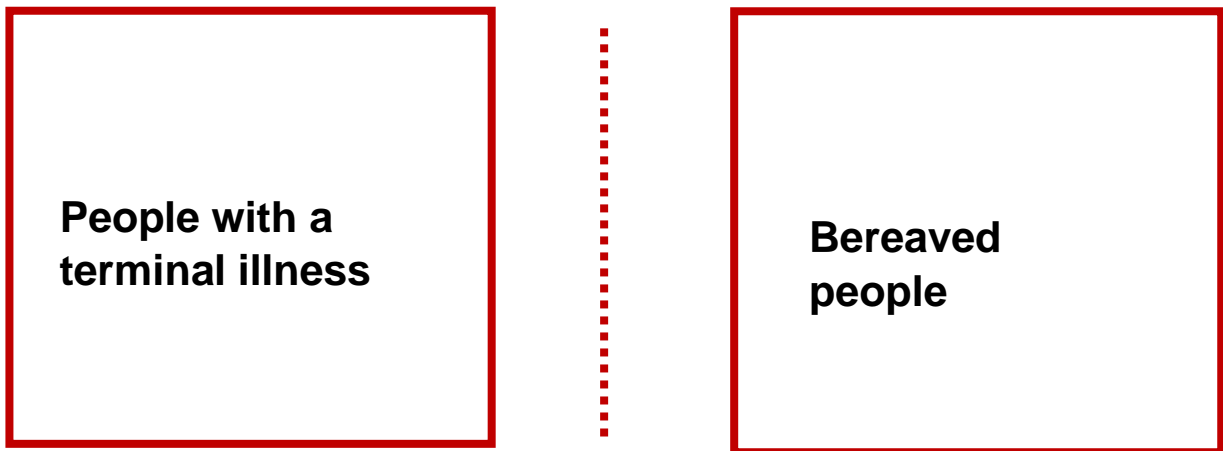


## About the research



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 the End of Life group.

The End of Life group includes the following:



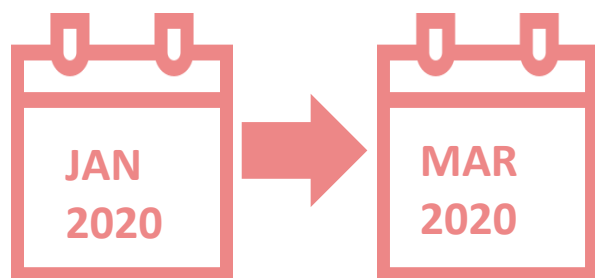
The research involved 11 participants: 5 participants living with a terminal illness, 5 carers of people with a terminal illness, and 1 bereaved participant.



**8**

**Interviews with  
11 participants**

The research took place between



The research explored views on:



Previous and current experiences of the benefit system



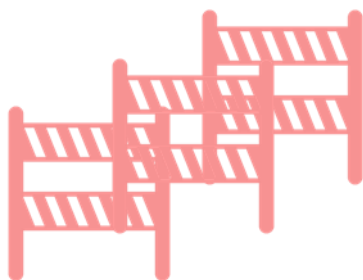
Finding out about benefit eligibility



Benefit application processes



Support to access the benefits system



Barriers to access benefits

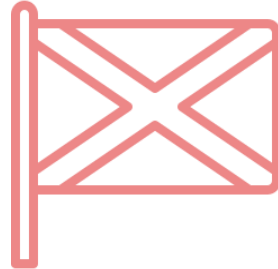


Improving the benefits system

## About the research participants

All participants were over

**40** years old



Respondents took part from **4** local authorities in Scotland



**8**

Female



**3**

Male

## Barriers



Participants did not know they were entitled to some benefits following a terminal illness diagnosis. Some did not look for financial support for some time after their diagnosis.



Some participants did not know that they could be entitled to other benefits.



Some participants said staff from government agencies did not provide them with information on benefits. A few also mentioned DWP staff treated them insensitively.



Participants found benefit application forms difficult to complete on their own because they were long and complicated. They relied on third sector organisations to help them fill in and submit forms.



Some said the timescale for processing applications was too long.



Participants said that travel to attend assessments and appointments can be a challenge when facing a terminal illness.



Some participants had barriers to access adapted vehicles and wheelchairs to attend appointments.



Some did not know what will happen with benefits for carers once someone with a terminal illness dies. Some carers did not know the impact on eligibility for Carers Allowance if receiving a state pension.

“Following the diagnosis, so many practical things kick in that you’re just swamped on every level while you’re also emotionally stunned. There’s no good way or time to give people financial advice when someone’s dying, but earlier on would have been better. As it was, we just left the hospital each time with nothing.”

[Participant who had lost partner to terminal illness]



## Views on improving the benefit system



Third sector organisations helped participants to get information on benefits and eligibility, and provided support to complete forms.



Most participants wanted clearer and more readily available information on benefits, eligibility rules, and on how to apply.



Several felt that health professionals could have a more proactive role in providing information on benefits. Some suggested that information about support available would be helpful at the point of diagnosis.



A couple of participants would like a fast-tracked process for accessing benefits in the context of a terminal illness.



Some recommended that benefit staff should receive more awareness training on issues that people dealing with a terminal illness diagnosis face. This would help ensure they were treated with empathy.



Having a single point of contact in benefit agencies to avoid repeating sensitive information was suggested.



Participants proposed a range of benefits-related communication channels depending on their needs, circumstances and personal preferences.



Preferences for home visits for benefits-related issues was mentioned by a few.



“When someone, whether it’s an accident or an illness, if there was an information pack just automatically given to them, I think that would be very helpful. If you’re at the GP and you’re seeing them anyway, it would be good to be given something then.”

[Participant with terminal illness and their carer]



## 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 the End of Life group had.



Insights on awareness of benefits and clearer information have fed into the provision of inclusive communication approaches. Social Security Scotland provides transparent and accessible information. Also, there are two [benefit take-up strategies](#) that set out all the activities being undertaken to ensure awareness of benefits improves.



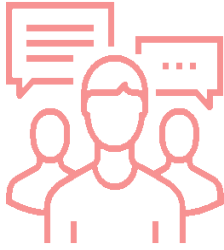
The design of Social Security Scotland benefit application forms have been developed with people experiencing the benefits.



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.



Insights on the key role third sector and advocacy 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.



Barriers to attend assessments and preferences for home visits fed into the development of the Local Delivery service in local communities across Scotland. The new service allows clients to book an appointment to meet with a specially trained adviser at a venue within their local community, or at their home. They are also able to request video call or telephone appointments.



Individuals who are applying for disability assistance and are terminally ill will be fast tracked to ensure the maximum support is available as quickly as possible.



When Scottish Carer's Assistance is launched, we will provide carers with information about support available to them. This will take into account particular stages of the carer journey, including when the cared for person dies.



The [Second Benefit Take-up Strategy](#) expands the access to welfare advice by funding the placement of welfare rights advisors in GP practices in Scotland's most deprived areas. These practices will be able to refer patients directly to an in-house welfare rights officer for advice and support.



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