SOCIAL SECURITY EXPERIENCE PANELS - SELDOM HEARD PROGRAMME OF RESEARCH: END OF LIFE

Equality, Poverty and Social Security

social research

Contents

Summary

Introduction

In 2017 Social Security Scotland set up Experience Panels to help in the design, delivery, oversight and review of Scotland's new social security system. These panels are made up of over 2,400 people who have experience of at least one of the benefits that have devolved to Scotland. However, hard to reach and marginalised groups are less likely to be visible in the Experience Panels. The 'seldom heard voices' research was consequently designed to ensure their voices are included in the design of social security services.

There are four groups identified as 'seldom heard' in this research. They are Mobile Populations, Vulnerable Groups, End of Life, and Carers and Care Experienced. For each group two waves of fieldwork are being undertaken.

This is the report for the first wave of the End of Life strand. This strand aims to explore the experiences of people living with a terminal illness (and their carers) or those who have been bereaved.

Background

All but one participant in the End of Life group either had experience of living with or caring for a partner with a terminal illness. The remaining participant had lost their husband to cancer. These circumstances created a range of health, financial and practical pressures on participants, which were often inter-related.

This report highlights key barriers and challenges in accessing benefits faced by End of Life strand research participants, as identified through analysis of qualitative interviews. The report also discusses enablers or potential improvements which may support increased benefit uptake among this group.

Summary Findings

Barriers

Research findings suggest that participants were often initially unaware they were entitled to benefits following a terminal illness diagnosis. This was possibly due to participants' limited prior experience of the benefits system, a lack of signposting as part of (initial) medical appointments, and health concerns initially dominating their focus. This meant some participants with a terminal illness and their families did not seek financial support for some time after their diagnosis. This is despite their health situation being the trigger for their need and eligibility for financial support.

Participants typically found benefit application forms challenging to complete on their own. Forms were seen as long and complex. This meant third sector organisations were strongly relied on for supporting participants through the application process.

Some participants reported challenging interactions with government agencies when trying to find out about or access benefits. They reported not getting the information required or being treated insensitively. This was not universal and some other participants reported more positive or neutral experiences.

Enablers

In discussion, participants also identified key enablers which had or would have helped them access the benefits system. Taking account of these factors may help make the benefit system more accessible in future for people facing similar circumstances.

Third sector organisations were found to be a key link for enabling participants to access financial support through the social security system. Most participants said such organisations were key for helping them understand that they were entitled to support and what specific benefits they could access. Additionally, several participants described the crucial role third sector organisations played in assisting them to complete application forms or filling them out on their behalf.

Most participants reported a need for clearer and more readily available information about what benefits are available, eligibility rules, and how to apply. Many felt a single source of information such as a leaflet or pack would be helpful.

Several participants felt that doctors and other health professionals could play an earlier and more proactive role in providing benefits information. This could be through the provision of an information pack as above or signposting to organisations who could help. A few mentioned that information about support available would have been helpful at the point of diagnosis specifically.

Introduction

The Social Security Experience Panels were established by researchers in the Scottish Government in 2017. Scottish Government researchers work with members to bring the voices of those with lived experience into the design of the new social security system in Scotland, as run by Social Security Scotland. There are groups of people with lived experience that are less likely to be represented on the panels, so the "Seldom Heard Voices" qualitative research programme was set up to address this gap. It ensures that groups who need to be treated with particular sensitivity and those who are marginalised or dispersed, also have a voice in designing social security services.

There are four groups identified as 'seldom heard' in this research programme. They are Mobile Populations, Vulnerable Groups, End of Life, and Carers and Care Experienced. For each group two waves of fieldwork are being undertaken.

This is the report for the first wave of the End of Life strand. The fieldwork was undertaken by KSO Research Limited between January and March of 2020. The analysis and reporting was carried out by Scottish Government researchers.

The second stage of research is in progress at the time of writing and is due to be published in 2022.

Research Methods

This strand of the research sought to explore the experiences of the social security system among two groups - those living with a terminal illness (and their carers) and bereaved people.

The research included eight interviews with a total of 11 participants. Five participants were living with a terminal illness. Three of them also had their partner carers take part in the interviews. A further two people caring for individuals with a terminal illness took part in interviews by themselves. One interview was completed with a participant who had lost their husband to a terminal illness. Research participants were typically either living with terminal cancer, MND or were carers of people living with these conditions. No interviews were conducted with parents of people on the basis of them having been bereaved in other contexts, such as parents of still-born children.

Participant demographics

Eight of the participants were female. The three male participants were all carers who had joined their terminally ill partners for the interview. All participants were aged 40 and over. The majority were over 50 years old.

Participants were based in Glasgow, the Scottish Borders, Falkirk Council and Midlothian. No further demographic information on participants was collected.

Participants were recruited via stakeholder organisations. Most participants were recruited as a result of their relationship with Macmillan Cancer Support or MND Scotland[1].

---

[1] MND Scotland is a Scottish charity providing care and support to people affected by Motor Neurone Disease (MND).

Interview method

The original expectation was for research to be undertaken using a combination of individual face-to-face interviews, paired interviews and focus groups with participants sharing similar experiences. Participants all had a preference for individual interviews for privacy.

Interviews were carried out between January and March of 2020. Fieldwork was halted in March 2020 in line with restrictions associated with the COVID-19 pandemic. Interviews were conducted by an independent research company, KSO Research Limited, commissioned by the Scottish Government. Interviews took place in the participant's home, with the exception of one which was in a neutral venue. Interviews lasted between 27 and 65 minutes.

KSO Research Limited did not disclose the identities of participants to Scottish Government researchers. All participants consented to participate after having been informed of their rights, including those relating to data protection. A £20 gift voucher was offered to thank people for their time.

Research Questions

The research was designed to help shape the new Social Security Scotland ensuring that it is built around people's needs. The interviews explored participants' experiences of and views on accessing benefits following a terminal illness diagnosis or being bereaved. This included questions on:

- Respondents' experience of the benefit system historically and in the current circumstances
- How they found out about benefit eligibility
- How they applied for benefits and their views on the application process
- Any support they had received to access and navigate the benefit system
- Any challenges encountered when trying to access benefits and views on where improvements could be made

Limitations

As participants were recruited through support organisations, their experiences may differ from those who do not access support from the third sector or other similar organisations. This should be kept in mind when interpreting the findings and considering how widely they apply to people facing terminal illness or bereavement.

Quotations

The Scottish Government research team received summaries of interviews from the research contractor rather than full verbatim transcripts. Where quotation marks are used in excerpts ("…"), this indicates direct quotations of participants. All other text included in excerpts represents the summarised note taking of the interviewer as below:

> **The wider support given by MND Scotland was praised and the couple felt that this was their main source of support moving forward:**
>
> **"They've taken the pressure off a bit and they can also give us a heads up of what we can expect."**
>
> [Individual with terminal illness and their carer]

General experiences of benefits

Participants were interviewed because they or someone close to them had been diagnosed with a terminal illness. One participant had recently lost their partner to a terminal illness. Discussions largely focused on participants' experience of accessing benefits in these circumstances. Participants reported their experiences of accessing benefits related to ill-health and disability, including Personal Independence Payment, Attendance Allowance and Carer's Allowance. However, most participants reported a lack of or very limited previous experience with the benefit system prior to the terminal illness diagnosis.

Several participants had been in employment up until their diagnosis and the benefit system was an entirely new area to them. This was also the case for some partners involved in the interviews who had given up employment to become carers for participants diagnosed with a terminal illness.

> **"We've both worked since we left school at 16…I've never been in a job centre and wouldn't even know how they work, to be honest."**
>
> [Carer for individual with terminal illness]

> **"Until then, we'd never claimed a thing in our lives."**
>
> [Individual with terminal illness and their carer]

This lack of experience provides important context for a number of the barriers and enablers to accessing benefits described by participants in this strand of the Seldom Heard research programme and outlined in this report. Additionally, it means participants were not able to provide a wider view on the system, changes over the years or comparisons between different benefit types.

Support networks and resources

The vast majority of participants reported that third sector organisations had been crucial for enabling them to access benefits and were clearly appreciative of their help. The organisations most commonly mentioned by participants were unsurprisingly Macmillan Cancer Support and MND Scotland given their key role in recruitment for the interviews. However, a couple of participants did suggest that the organisations they were engaged with should not have to be so heavily involved in providing support and advice related to benefits. One of them suggested that government should be responsible for this instead.

> **"And, although they've been great, they are a charity. It does seem like there should be a government agency or someone who can give you the advice, rather than a charity…It's an invaluable service that they're (Macmillan) providing but it's a pity that it's got to be a charity rather than an organisation that is government sponsored, or whatever."**
>
> [Individual with terminal illness and their carer]

A few participants also reported being given wider elements of financial and practical support by support organisations. For example, some had received help to access other grant funding or entitlements (such as Blue Badge parking permits).

Many participants noted that their interaction with a support organisation was a result of being signposted by a medical professional or through meeting a support worker in a medical setting.

Only a few participants mentioned getting advice about what they would be eligible for and how to make a benefits application from the Department for Work and Pensions (DWP) or other UK Government departments.

Some participants mentioned receiving advice about benefits and support from council employees. One participant noted exploring options available after hearing though word-of-mouth from other people with the same condition that there may be

support available. Another described receiving a letter from their employer at the end of their period of sick pay which said they might be entitled to 'benefits', but said this was fairly vague.

Finally, it is worth noting that some participants were also trying to arrange other sources of support that they required as a result of their health condition. This included home adaptations, and getting wheelchairs and accessible vehicles. Additionally many participants also spoke of the need to attend medical appointments or undergo operations. In some circumstances, these may represent additional demands on individuals' time and energy alongside navigating the benefits system, or also have financial implications for them and their relatives.

Key barriers experienced with the benefit system

As End of Life research participants described their experiences of navigating the benefits system, a range of challenges were highlighted. Key themes which could represent barriers to people in similar circumstances accessing benefits in future are summarised in the section below.

Lack of awareness about benefit eligibility immediately after diagnosis

One of the most significant barriers to accessing benefits amongst participants, at least initially, was a general lack of awareness they could be entitled to financial support following a terminal illness diagnosis. This may be in part due to a participants' limited prior experience of the benefits system. However, in this context, it is notable that many participants complained about not being given financial advice as part of medical appointments either at all or at any early phase. This meant some participants with a terminal illness and their families did not seek financial support for some time after their diagnosis. This is despite their health situation being the trigger for their need and eligibility for financial support.

A couple of interviewees described how they were eventually signposted to third sector organisations for advice. This came after a number of medical appointments or in response to them mentioning financial worries to medical staff. Relatedly, two participants explained how they did not give much consideration to financial concerns themselves initially as they focused on their, or their partner's, health condition.

"I mentioned to the nurse when I was at my appointment just before Christmas that I was worried about money, mainly my rent really…I had been in the hospital on and off since October but that was the first time I said anything. And then she put me in touch with [name] from Macmillan and she put us through what we needed to do and that."

"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."

[Individual who had lost partner to terminal illness]

"It was a few weeks after the operation that we started to think about money. At the time, money's not really on your mind. At the time, you're not thinking - you're thinking about health and thinking about other things. Obviously, although you need money and you need something to survive on, and that's always something to worry about, you try not to worry about it immediately."

[Individual with terminal illness and their carer]

Challenging interactions with government agencies about benefits

Some participants reported challenging interactions with government agencies when trying to find out about or access benefits. The issues centred around not getting the information required or being treated insensitively.

Only a few participants reported trying to initially find out about benefit eligibility from the DWP directly. All of them described this as challenging. One "spent hours looking at government websites" and had to make several calls to get clear advice about what they were entitled to. The other two participants ultimately had to get support from a third sector organisation to clarify their eligibility despite reaching out to DWP. One of them recalled particular difficulties navigating DWP's automated phone line and eventually being directed online, despite having limited internet access.

"The first time I tried to get in touch with the DWP, it's designed to put you off. Well, I spent all morning trying to look up numbers and they kept trying to direct us online. Now, I don't have a computer. I've got an email address on my phone, but I'm of an age where I'm not really that tech savvy. So, doing things online isn't for me…a recorded voice comes on and says "The

information you require is available at MyGov.UK and you're just cut off. It always ends with "Thanks and goodbye", and it just cuts you off."

[Individual with terminal illness and their carer]

A few participants also described their experiences of face-to-face appointments with DWP staff in job centres in the process of accessing benefits. A small number of participants reported that these interactions were generally fine. However, another participant had a particularly difficult experience where the staff member they spoke with was "really dismissive", made them feel "like a scrounger" and treated them insensitively when they disclosed the nature of their situation. That said, a second scheduled visit with a "more sympathetic and empathetic" member of staff was reported much more positively.

Experiences of feeling judged or being treated insensitively were also reported by other participants who had phone contact with the DWP and Her Majesty's Revenue and Customs (HMRC) respectively about financial support. However, aside from these experiences of difficult interactions, participants did not proactively mention stigma or feeling judged as a more general barrier which deterred them from accessing benefits.

"The [HMRC staff member] didn't present herself very well and was very matter of fact.…participant ended up having to speak to them on the phone and she ended up being upset the whole day by what they'd said. Just that because she was going to die, it meant there was a different way of doing things. Just to say it like that - that you're going to die - doesn't seem right."

[Individual with terminal illness and their carer]

Lack of certainty about other support potentially available

Even where participants had now been supported to access benefits, there remained a degree of uncertainty about other channels of financial support they could be entitled to. Some reported how they had heard of some benefits but did not think they were eligible as it had never been mentioned to them. This suggests participants relied heavily on advice about what specifically they should apply for.

This could represent a barrier if advice given is not comprehensive, accurate or on-going.

> **They felt that they might also be eligible for council tax exemptions or reductions, Universal Credit and Employment Support Allowance, but they were not sure and also not sure who to ask.**
>
> [Individual with terminal illness and their carer]

> **The respondent had heard of PIP but felt she didn't qualify and it had never been mentioned by the Macmillan nurses, so she only pursued Carer's Allowance.**
>
> [Individual with terminal illness]

Application forms too challenging to complete without support

More than half of interview participants highlighted that they found completing benefit applications challenging. Reasons outlined tended to centre around the forms being too long and complex to complete by themselves. Participants described them as "daunting", whilst another said they were "intimidating". For some, this seemed to be related to a lack of experience of, or familiarity with, filling in benefits application forms in the past.

Some participants were uncertain which parts of the form they should complete in their circumstances of living with a terminal illness. Furthermore, one participant said that the progressive nature of her husband's terminal illness meant summarising their challenges and needs at any one point in time was difficult.

As a result of these challenges, most participants had received help from a third sector organisation to complete and submit the forms. Two participants noted that they felt they would not have been able to make a successful benefits claim without this support.

> **The couple had attempted to complete the Carers Allowance application form, but found it unmanageable:**

> **"Up to that point, I had still been getting sick pay from work, and PIP. Again, I got the application form which was absolutely massive. I started doing that, and it asks you a lot of stupid questions, and you try and thingmy it out."**
>
> [Individual with terminal illness and their carer]

> **"It was like a book. Someone with experience is much better to fill these things in. The woman from Macmillan took a pen and crossed out pages just saying, "That's not relevant to you", but we didn't know…"**
>
> [Individual with terminal illness and their carer]

Other feedback on the wider application process

Some participants thought the timescales for processing applications was too long. Both noted that the context of them or their partners living with a terminal illness meant time was limited and so applications being processed quickly is important.

> **"But it was quite a lengthy process. Um, I realise that with some illnesses, and with the type of illness that I've got, it is terminal but you're getting worse all the time and you don't really have time to wait on the things that need doing."**
>
> [Individual with terminal illness and their carer]

A few participants noted challenges or negative experiences with meeting the wider needs of the benefits application process. For example, the need to travel to benefit assessments or for multiple appointments was noted as being difficult where mobility becomes more challenging as a result of a terminal illness.

One participant said having to verify their identity in order to apply for benefits was "stressful". The need to find specific documentation and share this with DWP was seen as an unhelpful demand of their time in the circumstances. This requirement was due to the fact they had not applied for benefits before. However, as this applied to many participants in the terminal illness based interviews, it could represent a potential barrier more generally for people in these circumstances accessing benefits.

> **Having to attend only one appointment to verify identity, complete medical assessments, etc. would have been better than multiple meetings, especially**

given her husband's mobility challenges and her own working patterns (i.e. she had to take time off to attend meetings with her husband).

[Carer for individual with terminal illness]

Link between financial and health needs

More generally, several participants mentioned facing financial and practical barriers when attending medical appointments associated with their condition. This included trying to arrange access to adapted vehicles and wheelchairs which would help them get around more easily. One participant noted that the need for their partner to have suitable transport and other practical support when attending appointments meant they had given up work to become a carer. Their partner noted that having additional funds for getting taxis to appointments would enable them to maintain independence.

Specific challenges experienced by carers

Finally, a few participants raised concerns or uncertainties about what happens with benefits for carers once someone with a terminal illness dies and how this would impact their finances. For example, one participant outlined the challenge this posed for them in trying to balance short- and longer-term financial security. They noted that they were advised by the DWP they might be better to give up work and claim for carer benefits. However, they thought this might put them in a more difficult position in terms of employment and finances in the future.

Two participants highlighted a lack of knowledge about how eligibility for Carers Allowance was affected by them already receiving the state pension. This suggests information on the interaction between different sources of support could be clearer.

"A few times, I got the impression that because of my job, we couldn't get anything, and I wondered if my husband would be better off if I wasn't working."

[Carer for individual with terminal illness]

Enablers and improvements for the benefit system

Positive experiences (enablers) around the benefit system were also identified through the interviews. Some participants also shared thoughts on how parts of the system can be improved. Key enablers and potential improvements are outlined below. Many of these points drew directly from the barriers experienced by participants outlined in the previous chapter.

Key role played by third sector organisations

Third sector organisations were reported as a key enabler for participants trying to access financial support through the social security system. Organisations helped most participants understand that they were entitled to support and what specific benefits they could access.

Several participants described the crucial role support organisations played in assisting them to complete application forms or filling them out on their behalf. As outlined in the barriers section, without this support some participants suggested they would have been unable to make a successful application.

> **After Macmillan had completed a new application, the participant had been sent a copy to read and sign in her own time which was much more relaxed and less stressful, she explained.**
>
> **"Oh, it was brilliant - she [the Macmillan nurse] knew how to go about it. What questions to answer, what not to answer, not all this kind of confusion, I mean, I was at a total loss."**
>
> [Individual with terminal illness]

> **"[The MND Scotland] representative came down to the house and helped us fill in the form. It was quite lengthy but it was fine. It was far easier with them being there. We'd looked at it and just felt it was a bit daunting so we contacted the lady there and she was very helpful…"**
>
> [Individual with terminal illness and their carer]

One participant recalled that they had been helped with the application form by a Welfare Rights officer from the local council. Similar to those working with third sector organisations, this enabled them to complete a task they said they could not have done on their own.

Third sector organisations were also credited with helping some participants navigate the requirements of the benefits process more generally. For example, one participant described how they were advised that they were not obliged to attend further appointments to discuss their Personal Independence Payment claim after the initial interview, despite receiving requests from the benefits agency.

A few participants also mentioned being prompted by a third sector organisation to gather evidence about their condition and prognosis from their GP in order to support their benefits claim. When asked what evidence had been submitted alongside their application, most participants had not heard of a DS1500 form[2] or were unsure if this was definitely the form which had been provided. This suggests that participants were not always clear on the specific details of official documents required to support a claim and relied on third sector support to navigate the process. This could represent a barrier for anyone trying to go through the benefits application process themselves.

> **"You got a letter from the doctor to forward and took that to Macmillan. Macmillan told me to get that, a letter with my prognosis, and we gave that to Macmillan."**
>
> [Individual with terminal illness and their carer]

Improved information about benefits

Most participants reported a need for clearer and more readily available information about what benefits are available, eligibility rules, and how to apply. Many felt a single source of information such as a leaflet or pack would be helpful.

---

[2] As part of benefit applications in the context of a terminal illness, a DS1500 form can be completed by a medical professional. It outlines an individual's diagnosis and treatment plan to support the application. It can also help applications be processed more quickly.

> **"It would be handy if, when you've got a disability, if there was an information pack sent out by DWP that told you what you may and may not be eligible for. And, I know you can look things up online, but it is a bit of a minefield. It needs to be explained in plain language, and not everyone can access the computer..."**
>
> [Individual with terminal illness and their carer]

A couple of participants suggested that people diagnosed with a terminal illness need a package of information with financial information provided alongside rather than simply in addition to medical and other practical advice. This would help them navigate the range of issues they might face and access suitable support.

> **"For me, in an ideal world, the thing that would have made a massive difference is having a multi-disciplinary package of information from the get go. I honestly think that would be life changing for people and that would have let me concentrate on the time that I had left with my husband."**
>
> [Individual who had lost partner to terminal illness]

More proactive financial advice from health professionals

Several participants felt that doctors and other health professionals could play an earlier and more proactive role in providing benefits information. This could be through the provision of an information pack, as mentioned above, or signposting to organisations who could help. A few mentioned that information about support available would have been helpful at the point of diagnosis specifically.

> **"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."**
>
> [Individual with terminal illness and their carer]

> **"In hospital, maybe after the op, give me details there - I thought the doctors might be better qualified to tell me, give me some leaflets or something to let me know what I qualified for."**
>
> [Individual with terminal illness]

Greater awareness raising about benefits

One participant suggested that leaflets in hospital waiting rooms would be a good way to generally raise awareness of benefit entitlement amongst people with health conditions. Another participant called for more widespread dissemination of information about benefits in public settings (such as health centres or libraries) or through the media. They noted that different sources might be accessed by different groups and so a diverse approach might be useful. Beyond this, no further views were offered on how information about benefits could be promoted more generally.

Desire for a 'fast-tracked' process

A couple of participants specifically expressed a desire for a fast-tracked process for accessing benefits in the context of a terminal illness. It is unclear whether this is because they did not recognise that such a scheme is in place, or simply felt things should be faster still.

> **"Things need to be speeded up a bit and probably if things could be fast tracked for people who do have terminal illness that would be better. I know there's a lot of different terminal illnesses, and for some you can live for a long, long time. But for others, you can't. So being able to fast track is really important."**
>
> [Individual with terminal illness and their carer]

Specialist and empathetic benefits staff

A few participants highlighted scope for benefits staff to have greater awareness of the issues faced by individuals and carers dealing with a terminal illness diagnosis or bereavement. Participants suggested this would help ensure they were treated sensitively.

One participant described how appreciative they were that support workers in third sector organisations had treated them so well. This was noted as example of contact and support which had worked well.

> **"It wouldn't be bad if Social Security Scotland had at least one member of staff who had specialist training in dealing with situations like this. And, if someone's role was to deal with people who had bereavement and grief issues, that couldn't do any harm."**
>
> [Individual who had lost partner to terminal illness]

Continuity when interacting with benefits staff

Two participants suggested having a single point of contact in benefits agencies when making applications would be useful. This would help cut down on having to repeat sensitive information about their circumstances to different people on multiple occasions. One described how this continuity might help in cases where people were making claims for multiple benefits in particular. Another participant suggested that generally minimising the sources of communication and people involved in care and support provision may be appropriate.

> **"Someone that knows your circumstances, so you don't have to keep repeating yourself. Someone who knows from the word go what you're going through and can help you through the whole thing."**
>
> [Individual with terminal illness and their carer]

Varied communication preferences

Participants offered a range of views on communication preferences. Taken together, the feedback gathered indicates a range of needs or desires which vary across different types of correspondence, circumstances and personal preferences. This suggests that multiple channels for benefit-related communication and information are important.

A couple of participants noted that they would prefer face-to-face communication for initially finding out information about benefits and eligibility. For one participant, this was particularly important in the context of a terminal illness or bereavement as it would offer them the chance to make sure they got all the information required.

> **"Having face-to-face contact in these cases makes a world of difference. And I don't think that's any different depending on the relationship. Anyone who you love and care about really, it's about clarity. And the thing that face-to-face can do that a letter can't is that you can respond. You can ask questions and get more clarity that way."**
>
> [Individual who had lost partner to terminal illness]

However, several participants expressed a desire for benefits-related correspondence, such as decision letters and updates, to come in the form of letters. This would provide a record of what was communicated, and also give participants the chance to read things multiple times and digest information. One participant noted that letters are accessible to all age groups and noted that they felt more personal than emails.

A few participants suggested that letters could be improved to offer more clarity and explanation of the information being communicated and options available. However, this was not a consistent view with some other participants noting that letters received had been clear enough for them.

> **"When you've got something in black and white, you've got proof."**
>
> [Individual with terminal illness and their carer]

> **The respondent expressed a preference for receiving written letters rather than phone contact because "Sometimes you need to read them 2 or 3 times to understand what they are saying".**
>
> [Carer for individual with terminal illness]

No participants expressed a specific desire to access benefits information over the internet. In fact, some participants reported having limited internet access and IT

literacy skills. This meant both found benefits information available online less accessible.

Interest in home visits

A couple of participants mentioned a preference for home visits for benefits-related issues or contact with government agencies more generally. In both cases, this was related to their health condition.

> **"It would be better if people came to us now, instead of us having to go to appointments, because [name] just isn't confident leaving the house, even though support from our neighbours has been good, she wouldn't want to go into town."**
>
> [Individual with terminal illness and their carer]

Greater advice for carers about their financial future

Finally, one participant highlighted a desire for benefits agencies to offer more reassurance and advice to carers for individuals with a terminal illness about their longer-term finances. They felt this would help reduce some of their anxiety. This reflects the uncertainty noted by some carers about the future of their benefits as discussed in the 'Barriers' section of the report.

What's next?

The chart below summarises the barriers that carers and care experienced people faced, the corresponding enablers and suggested improvements and sets out the action Scottish Government and Social Security Scotland will undertake (or has already undertaken) to address these barriers.

Barriers	Enablers	Action
Lack of awareness of benefit eligibility	Greater awareness of benefits	A general duty to promote the take-up of devolved benefits is enshrined in the [Social Security (Scotland) Act 2018](#). Social Security Scotland and the Scottish Government to date have published [two take-up strategies](#) that set out all the activity and engagement being undertaken to ensure awareness of benefits improves. Social Security Scotland will build on these findings by carrying out further research to identify and explore how best to communicate and market benefits to hard-to-reach and marginalised groups. The results of this research will be used to develop bespoke communication and engagement plans to support communication activity.

		The findings from this research have been fed into the consideration to implement a joined-up approach to improve access to information and support, and the importance of providing a range of communication options, in the work to develop Scottish Carer's Assistance, the Scottish replacement benefit for Carers Allowance. The intention is for the new benefit to reach more carers, and help carers find out about the wider support which is available to them.
Lack of certainty about support available	Varied communication preferences

Interest in home visits | For the benefits that have been and will be devolved to Scotland Social Security Scotland will offer a range of ways to apply for the benefits they deliver including online, telephone, paper-based or face-to-face. Further applicants will be offered support when applying for disability benefits. This multi-channel approach will ensure that those who cannot or choose not to adopt digital methods will not become isolated through technology.

The findings on the preference for face-to-face support will be fed into the development of the Local Delivery service in local |

		communities across Scotland. This service will be person-centred by providing local presence to meet people's needs in key locations where clients currently attend. Local delivery staff will provide pre-application advice and support to encourage people to take up the payments they are entitled to.
Challenging interactions with government agencies about benefits	Specialist and empathetic staff	Social Security Scotland and Scottish Government have gone to great lengths to ensure that fairness, dignity and respect are embedded in the new system. Our Charter was co-designed to ensure that what a good system looks like is set out in full. This system includes the need for staff to be knowledgeable and empathetic. The Charter Measurement Framework (also co-designed) monitors and reports on a yearly basis the progress being made against the Charter.
Application forms too challenging to complete without support	Clearer and more readily available information	Social Security Scotland has introduced inclusive communication approaches in all its work; working towards clear and accessible information, and a clear and transparent explanation of the eligibility criteria for each application form.

| | | Further, the design of forms and application processes are undertaken in collaboration with people with lived experience of the benefit being devolved. There is also a shorter, simpler application form for each of our new forms of disability assistance where the individual is applying through the 'special rules for terminal illness' route.

Social Security Scotland has provided telephone and online services to advise clients on each aspect of the application processes. |
| --- | --- | --- |
| | Key role played by third sector organisations to access the benefit system | Scottish Government has published two take-up strategies that include engaging with advocacy organisations to address barriers to benefit take-up. The findings from this research will inform a targeted approach with these specific groups for the implementation of interventions committed to in the Benefit take-up Strategy.

The findings from this research will be used to inform stakeholder engagement which communicates changes on Social Security Scotland benefits. Activities include |

		workshops which bring together a wide range of organisations. These workshops involve various teams across Social Security Scotland working with third sector organisations. This engagement will help organisations to provide relevant and accurate information on benefits and their eligibility to their clients.
Financial and practical barriers when attending appointments		The development of the Local Delivery service will be person-centred by providing local presence to meet people's needs in key locations where clients currently attend.
Long timescales for application processes	'Fast-tracked' process in the context of a terminal illness	All individuals who are applying for disability assistance because they are terminally ill will be fast tracked to ensure the maximum support is available as quickly as possible.
Challenges experienced by carers: lack of knowledge of Carers Allowance and uncertainty of benefits after person with terminal illness dies	Greater advice for carers about financial future	Local authorities have a duty under the Carers Act to provide information and advice services for carers, including advice on income maximisation. When we launch Scottish Carer's Assistance, our replacement for Carer's Allowance, we will provide carers with information about wider support available

		to them. This will take into account particular stages of the carer journey, including when a cared for person dies.
	More proactive financial advice from health professionals	The [Second Benefit Take-up Strategy](#) expands Welfare Advice and Health Partnerships through the funding of £2.9 million over three years to place welfare rights advisors in up to 150 GP surgeries in Scotland's most deprived areas. To date, more than 50 surgeries have begun to deliver this service, and all 150 surgeries will have an embedded welfare rights worker by January 2022. These practices will be able to refer patients directly to an in-house welfare rights officer for advice on increasing income, social security eligibility, debt resolution, housing, and employability issues as well as helping with representation at tribunals.

Further to the next steps outlined above, Social Security Scotland will also undertake a full assessment of the impacts and corresponding actions required as part of their business planning and prioritisation process.

The Scottish Government is doing further research with Seldom Heard voices.

KSO Research Limited is doing a second wave of fieldwork with End of Life research participants. We will publish the findings in 2022. Participants are being recruited through stakeholder organisations. These organisations offer support to both adults living with terminal illness, their families and carers; and to people experiencing bereavement.

How to access background or source data

The data collected for this social research publication:

☐ Are available in more detail through Scottish Neighbourhood Statistics

☒ May be made available on request, subject to consideration of legal and ethical factors. Please contact socialsecurityexperience@gov.scot further information.

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