

Social Security Experience Panels - Seldom Heard Programme of Research: Wave 2 report



EQUALITY, POVERTY AND SOCIAL SECURITY

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Executive Summary

This report presents results for the second wave of the 'Seldom Heard Voices' research programme. It includes findings with Vulnerable Groups, End of Life, Carers and Care Experienced, and Survivors of Abuse strands. The research was designed to engage with these Seldom Heard groups to better understand their experiences and views of benefits.

The research took place from October 2020 to December 2021. In total, 67 participants from the Seldom Heard strands took part in interviews. It also involved an online survey completed by 24 respondents from the Carers and Care Experienced strand. The sections below provide an overview of the main findings and themes which emerged from this research.

General experiences of benefits

Interview participants and survey respondents had diverse experiences with benefits. Benefits they frequently applied for were Universal Credit (UC), Child Benefit (CB) and Personal Independence Payment (PIP).

Communication channels for information and application processes

People across the Seldom Heard groups found benefit information from a range of sources such as online searches, support organisations, word of mouth, benefit staff, and public sector workers from health services and local authorities.

Mixed views were conveyed concerning how easy it was to get information. A few respondents and participants mentioned that it was easy to get information online. However, several highlighted the difficulties they had finding information from different channels.

Survey respondents and interview participants used various communication formats to make benefit applications: online, by paper, by telephone, and in person with benefit staff. Most participants found the application processes difficult with a few noting that it was an easy process.

Support with navigating the benefit system

Many reported a strong reliance on support workers from third sector organisations. They said they gave them support for finding information on benefit entitlement, completing the applications, and signposting further services. Others reported getting help from support workers from local authorities and their informal networks. Mixed views were identified in relation to support from benefit staff from Department for Work and Pensions (DWP) and Jobcentre Plus (JCP).

The effects of the Coronavirus pandemic on accessing the benefit system

Around a fifth (21 per cent) of survey respondents noted it was not easy to find out about the impact of coronavirus, furlough, and self-isolation on benefits. Over a half (54 per cent) said they were not sure. Survey respondents who provided some

explanation of why it was not easy mainly noted confusion when having to look for information.

When communicating by phone during the pandemic, a few interview participants experienced long waiting times getting benefit information or checking on the progress of their applications. Others also highlighted long waiting times for the outcome of their applications or arranging phone appointments.

Views on benefits being devolved to Scotland

Participants from the Vulnerable Groups strand were asked about their views of some benefits being transferred to Social Security Scotland. A few were not aware of the changes in the administration of some benefits. Mixed views were conveyed when being told about the changes.

A few participants thought this change will affect positively and they were hopeful that clients will have more help when accessing benefits. Others raised the following concerns and fears regarding the transfer of some benefits to Scotland: data security, the need to reapply, and the decrease of their current payments.

Key barriers with the benefit system

Difficulties finding information

Several participants and respondents highlighted the difficulty of finding information about what benefits they may be entitled to. Some mentioned that this resulted in avoiding start claims, missing out or delaying access to the benefits there were eligible for.

For many the information was unclear, confusing, and contradictory. They mentioned there are several sources of information, but it is not streamlined nor clear. Others thought that benefit staff from Department for Work and Pensions and Jobcentres were not transparent about providing information about potential eligible benefits to clients. A few highlighted the complexity of navigating government websites.

A small number of participants reported they were not told about their eligibility to passported benefits and they only found out about them circumstantially. Many said they knew about their eligibility to benefits by chance.

Complexity of application forms

Many participants and respondents felt that the application forms were lengthy and complicated. The wording of the applications was considered complex and not user friendly. Some mentioned that the questions were too prescriptive and repetitive and they did not allow them to capture the nature of their health conditions or their particular circumstances. Others felt that the questions were designed to avoid successful claims.

Challenges when accessing the benefit system online

Many highlighted the challenges related with applying to benefits online. These include not having access to a computer or a smartphone, not knowing how to use them, and not having access to internet. Some participants also thought that people who are not computer literate may feel embarrassed and struggle to get help.

Gathering information and evidence for application processes

Some participants reported various challenges for getting personal information or evidence required as part of their application processes. A number of participants from the vulnerable groups, in particular those who experienced homelessness or were in custody, highlighted challenges because they did not have a permanent address, a bank account or an identity document to start and follow up benefit applications.

Some noted that getting evidence related to mental health conditions was difficult. Related to this, a small number of participants felt that the medical evidence they provided was not recognised as much as it should be as part of their medical assessments.

Health assessments

Many participants experienced stress and humiliation when attending health assessments. Some thought the process of medical assessments is dehumanising. Others noted the questions during the assessment were closed questions based on a tick-box exercise with no room to account for fluctuating health conditions, in particular mental health conditions. A few thought the assessments were purposefully designed to make it hard to get successful benefit claims.

Some participants felt that that the views and comments of assessors were subjective. They thought that the outcomes of the benefit award decisions were the result of chance, mainly depending on the subjective comments of the assigned assessor. A few were critical about the frequency of health reviews for some long-term health conditions unlikely to change.

Stigma and distrust from the benefit system

Many participants felt discriminated and stigmatised against when interacting with benefit staff and when applying to benefits with the Department for Work and Pensions and Jobcentres. Some participants said they felt the whole culture of the benefit system is underpinned by distrust and suspicion towards the client. They felt frequently judged for relying on benefits and not being in paid work.

This negative perception towards the benefit system made many participants anxious and stressed when having to carry out benefit processes. A few mentioned that going through these processes exacerbates their mental health conditions.

Waiting times and financial hardship

Several participants gave accounts of the lengthy waiting times for various benefit processes. They reported how these waiting times made them experience financial hardship.

Many participants who had experiences with UC processes highlighted that the waiting times for their first payments were too long and impacted negatively on their finances. Some participants also experienced lengthy waiting times for getting award decisions, mostly for some disability related benefits like PIP or Disability Living Allowance (DLA).

Many participants reported that the lengthy waiting times for getting payments and receiving award decisions caused them financial difficulties such as a needing to use foodbanks, borrowing money and relying on their family networks to get by.

Many participants expressed their views in relation to the value of benefit payments being too low, and not matching the cost of living. Others thought the value of the payments were low because it deters people to rely on benefits.

Enablers and views on improvement of the benefit system

Multi-channel access

Across the Seldom Heard groups, suggestions of having a range of choices to access information, to apply to benefits and to get support were conveyed. Many thought the provision of various channels of communication would suit the different needs, circumstances, and preferences of clients.

Interview participants and survey respondents had a range of preferences for how to access information, how to apply for benefits and how to get support. These included: online, written information, telephone, and face to face communication.

Comprehensive and streamlined information

Many participants highlighted the importance of providing information that is accessible, easy to read, clear, and in plain English. They said the information should contain comprehensive information about eligibility, levels of funding, and various application processes. Others suggested the provision of a dedicated point of contact which focuses on giving all the information and support about benefits.

A single point of contact

Some suggested having a single point of contact to avoid repeating their personal experiences, needs, and health conditions. They also recommended a single point of contact as it would simplify the benefit system, help to have clear communication, and reduce waiting times.

Some participants mentioned that benefit staff should provide guidance and signpost specific services that support the needs of specific groups. A few participants highlighted the need for a fast-tracked process for accessing benefits in the context of terminal illness and progressive health conditions.

Specialist and empathetic staff

Many participants wanted the benefit staff to be fully trained and have regular updates on the system so they can provide comprehensive information about

benefits, interaction across benefits and benefit changes. Many also mentioned that staff should be trained to understand the specific circumstances of different groups such as survivors of abuse, terminal illness and bereavement.

Waiting times

Many participants proposed reducing waiting times between application and payment so clients could prevent falling on financial hardship. A few suggested that the value of the benefit should increase to cover a minimum standard of living.

Simplification of application processes

A few recommended the ability to track progress and updates of their applications. A few had positive experiences related to being given updates and reminders by email and texts. A small number of participants highlighted the need to have more updates so they can manage their finances better and feel less uncertainty.

A few participants thought it would be useful if personal information and evidence of the client could be stored centrally so they could avoid repeating their circumstances.

Health Assessments and renewals

Some participants suggested that health assessments should be carried out by medical professionals as they have the expertise to understand physical and mental health conditions and their impact on daily living.

Some mentioned that medical evidence provided by hospitals and General Practitioners (GP) should carry more weight for health assessments and award decisions. A few argued to reconsider the frequency of assessments for clients who have long-term conditions which are unlikely to change.

Flexibility in the system and wider support

A few participants highlighted that the benefit system needs to be designed with more flexibility so individual situations and sudden change of circumstances of clients are taken into account.

Some participants recommended the provision of specialised and wider support alongside the help with benefit payments. A few suggested the provision of specific and tailored employment support.

Third sector support

Support from third sector organisations contributed to positive experiences with the benefit system. Many participants and respondents mentioned how they were helped by support workers from third sector organisations on different aspects such as providing clear information, completing applications correctly and attending assessments and appeals.

Background and methodology

Background

The Scottish Government is responsible for some of the benefits previously delivered by the Department for Work and Pensions. As part of the work to prepare for this change, the Scottish Government set up the Social Security Experience Panels. Panel members are people from across Scotland who have experience of at least one of the benefits coming to Scotland. Over 2,400 people registered as Experience Panels members when it launched in 2017.

Scottish Government researchers work with panel members to bring the voices of those with lived experience into the design of the social security system in Scotland. However, there are groups of people with lived experience that are less likely to be represented on the panels. The “Seldom Heard Voices” 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 Scotland’s social security services.

There are four strands identified as “Seldom Heard” in this research programme. They are: Mobile Populations; Vulnerable Groups; End of Life; and Carers and Care Experienced. For each strand, two waves of fieldwork were undertaken¹. Additionally, fieldwork with a fifth strand, Survivors of Abuse, was undertaken in the second wave of fieldwork. The fieldwork was commissioned by the Scottish Government to the research companies and organisations shown in Table 1. The analysis was carried out by Scottish Government researchers.

Table 1. Companies/organisations that conducted fieldwork for the Seldom Heard strands

Seldom Heard strand	
Diffley Partnership	Mobile Populations ² and Vulnerable Groups
Blake Stevenson	Carers and Care Experienced
KSO Research Limited	End of Life
Scottish Women’s Aid	Survivors of Abuse

¹ All the Seldom Heard groups that participated in this research programme can be found in Annex A.

² Findings of the first and second wave of the Mobile Populations strand can be found on this report: [Social Security Experience Panels – Seldom Heard Programme of Research: Mobile Populations](#).

The findings of the first wave of the 'Seldom Heard Voices' research programme and the findings of the two waves of the Mobile Populations strand have already been published. The publications can be found on [the Experience Panels publication website](#).

This is the report of the findings for the second wave of the Vulnerable Groups; End of Life; Carers and Care Experienced; and Survivors of Abuse strands. This report also includes in Annex B suggestions provided by the research companies concerning engagement and recruitment with the seldom heard groups they worked with.

Methodology

The main aim of this research programme was to engage with Seldom Heard groups to better understand their experiences and views of benefits. Data were collected using qualitative interviews and an online survey with the Carers and Care experienced strand. There were a total of 67 interview participants and 24 survey respondents.

All the data collection was compliant with Social Research Association Ethical Guidelines, the Data Protection Act 2018 and the General Data Protection Regulation (GDPR). To ensure the research was ethically comprehensive, the following key mechanisms were applied: voluntary participation, informed consent, confidentiality and anonymity. Personal and sensitive data of participants was safeguarded and concealed. The data transferred to Scottish Government researchers for analysis were fully anonymised.

The research explored the experiences and views of participants about the following themes:

- Getting information about benefits
- Applying for benefits
- Interacting with government agencies, support and advocacy organisations
- Views on the future of the social security system in Scotland

Most participants were recruited through several stakeholder organisations. This targeted recruitment mainly included engagement with advocacy and support organisations that work around the needs of these specific groups. Hence, caution should be taken when interpreting the findings as they are not representative of all the population of these groups Seldom Heard groups. Those who do not access or are not linked to support organisations may have different experiences.

Interviews

All contractors used semi-structured interviews as the research method to elicit data.³ Most fieldwork was conducted by phone or video call between October 2020 and December 2021.⁴ A total of 67 interview participants took part in the research (see Table 2). A full breakdown of the number of participants by seldom heard groups is shown in Annex C. A gift voucher was offered to each interview participant as a thank you for taking part.⁵

Table 2. Timescales of fieldwork

Strand	Timescales	Number of participants
Carers and Experienced	Care October 2020 – December 2021	24
End of Life	February – October 2021	16
Vulnerable Groups	May – October 2021	24
Survivors of Abuse	June 2021	3

Quotations from the interviews are used to illustrate the findings discussed in the report. Edits to improve readability were made as appropriate. Those who took part in an interview are referred to as interview participants or participants throughout the report.

Online survey with Carers and Care Experienced groups

As part of the fieldwork with the carers and care experienced strand, an online survey ran between March and April of 2021. A total of 24 respondents completed the survey. Most of the respondents were single parents (58 per cent) and kinship/foster carers and adoptive parents (42 per cent). See Table 3 for more details.

³ Two interviews were conducted with two participants.

⁴ Interviews with participants who had experience of homelessness were conducted face to face in the premises of support organisations when the pandemic restrictions were lifted in August 2021. The following health protocols were applied: lateral flow test before and after the interview, social distancing, hand sanitizer and face masks.

⁵ Each contractor offered either £20, £15 or £10 gift voucher to each participant (four participants as part of the End of Life strand requested donations to nominated charities instead of receiving a gift voucher). Participants who were in custody did not receive any financial incentive.

Table 3. Groups survey respondents belong to [select all that apply] (n=24)

Carers and Care Experienced groups	%
Carers experienced	17
Single parents	58
Kinship/foster carers and adoptive parents	42
Young parents	17

Results shown in the report exclude any respondents who were either filtered out of the question or who left the response blank. Results presented in tables are intended to show proportions between different answer options. The number of respondents answering a question is shown in the title of the table as (n).

Quotations are taken from comments left by respondents in open-text questions. Minor edits to spelling and grammar were made as appropriate. We refer to those who completed the survey as respondents or survey respondents throughout the report.

Demographics

Information provided by interview participants and survey respondents was collated to present their demographic characteristics. The following demographic information is included to give context to the findings of this report. A full breakdown is provided in Annex D.

Most participants and respondents were based on Glasgow (26 per cent). Participants and respondents were also based on Fife (14 per cent), Edinburgh (10 per cent), North Lanarkshire (8 per cent) and Aberdeenshire (6 per cent). The majority were white (74 per cent). Over half (56 per cent) said they had a disability, long-term condition or infirmity.

More women than men took part in this research: slightly over two-thirds (67 per cent) were female. The majority were aged between 25 and 54 years old (79 per cent). Over half (53 per cent) cared for an adult or child with long term health condition, or an adult who needs support due to old age.

About the report

The report covers a wide range of themes explored during the second wave of fieldwork with Vulnerable Groups; End of Life; Carers and Care Experienced; and Survivors of Abuse strands. It is divided into three thematic chapters.

The first chapter includes the general experiences of seldom heard groups focusing on the various communication channels participants and respondents used for information and application processes, the support they had with navigating the benefit system and the impact of the pandemic on accessing it. The final section of this chapter includes the views of some participants of the benefits being devolved to Scotland.

The second chapter explores the main barriers and challenges participants and respondents faced when accessing the benefit system. Those include the difficulties they find with accessing information, their views of and experiences with the application forms, the challenges they faced when accessing benefits online and the barriers they experienced with collating information and evidence for their applications. This chapter also includes their negative experiences with health assessments, their views of the benefit system and the challenges they experienced with waiting times and benefit changes.

The third chapter explores the enablers and views on improvement participants and respondents have of the benefit system. Those include the need for various channels of communication, streamlined information and empathetic benefit staff. The chapter also gathers views on waiting times, simplification of processes, and assessments and renewals. It also includes views on providing a flexible benefit system and wider support. Finally, the third chapter gather positive experiences with third sector support.

A fourth chapter summarises in a chart the barriers and suggested improvements with key actions The Scottish Government and Social Security Scotland will undertake (or has already undertaken) to address them.

Finally, Annex B shows suggestions and insights provided by the research companies related with engagement and recruitment with the seldom heard groups they worked with. Annex E provides main challenges and views of improvement for specific groups of participants: prisoners, survivors of abuse, and bereaved people.

The data analysed in the report presents a range of views from seldom heard groups who participated in the research. Most data used in the report is qualitative and as such, findings are not always quantified; however, they provide a sense of how many people have highlighted key themes emerged from analysis of the interviews.

General experiences of benefits

Interview participants and survey respondents had diverse experiences with benefits delivered by the Department for Work and Pensions, Social Security Scotland, and local authorities. Table 4 shows that the most common were: Universal Credit (48 per cent), followed by Child Benefit (25 per cent) and Personal Independence Payment (22 per cent).

Table 4: Benefits claimed (n=91)

Benefit	Number	%
Universal Credit	44	48
Child Benefit	23	25
Personal Independence Payment	20	22
Five Family Payments ⁶	12	13
Child Tax Credits	11	12
Disability Living Allowance	10	11
Employment Support Allowance	8	9
Funeral Payment	7	8
Cold Weather Payments and Winter Fuel Payments	6	7
Housing Benefit	6	7
Carer's Allowance	4	4
Scottish Welfare Fund	3	3
Kinship Carer Allowance	2	2
Attendance Allowance	2	2
Young Carer Grant	1	1
Income Support	1	1
Industrial Injuries	1	1

⁶ The Five Family Payments are: Best Start Grant - Pregnancy and Baby Payment, Best Start Grant - Early Learning Payment, Best Start Grant - School Age Payment, Best Start Foods and Scottish Child Payment. It includes participants/respondents who received at least one of them.

Communication channels for information and application processes

Table 5 sets out the sources of information about benefits for survey respondents. Similar proportions (28 per cent) found information about which benefits they are entitled to: online, by organisations/professionals and by friends/family which gave them information. Less than one fifth (17 per cent) said a Jobcentre Plus advisor told them. Interview participants also found information through various sources.

Table 5: Thinking about the most recent benefits application you made, how did you find out about which benefits you are entitled to? (n=18)

	Number of respondents	% of respondents
Other organisations/professionals gave me information	5	28
Friends/family gave me information	5	28
I found information online	5	28
A Jobcentre Plus advisor told me	3	17

Mixed views were conveyed concerning how easy it was to get information. A few survey respondents and participants mentioned that it was easy to get information online. They highlighted that it was easy to look for information using the internet, online searches, and specific websites. A few mentioned that they used more than one source to get information about benefits. Those sources included: word of mouth, benefit staff and public sector workers from health services and local authorities. Many also reported getting information from relatives, friends, acquaintances, and peer and fellow service users.

“If I need information, I’ll just Google it. I was always quite tech savvy cos’ you get taught that at school. I know my way around a computer. I’ll ask Terrence Higgins Trust or my friend [name], or I’ll call the Citizens Advice Bureau. So, between those, I’ll usually get an answer.” (Vulnerable Groups strand, participant with HIV)

“I found out about the Scottish Child Payment through my sister. [...] and I had a support worker that was supporting me during my first pregnancy, and she was the one that kind of helped me know what I could apply for and what I could fill in for as I had no clue.” (Carers and Care Experienced strand, single parent participant)

Several highlighted the difficulties they had to find information from different channels⁷. Many reported their difficulties of using and accessing digital technologies: not having access to internet or/and computers, not knowing how to use smartphones and computers, and not knowing which websites to look for information.

“I wouldn’t say it was easy to find out, but I did get a lot of help from the people from the job centre. I’m not very good on phones and technology. I could build you a house. But technology I need to brush up on. I’m not very good at emails and covering letters and all that.” (Vulnerable Groups strand, homeless participant)

However, a few highlighted that they were computer literate so they were able to find the right information about benefits. A small number of participants noted differences between how easy it was finding information of some benefits, but not about other ones.

“I’m pretty confident using the computer. I don’t have one myself but the library was brilliant. It’s free and you just go in and there’s a computer you can use.” (Vulnerable Groups strand, prisoner participant)

“...Child Benefit was easy enough because the criteria for it are quite straightforward. Most other things I've found my earnings are too high, but sometimes finding what those thresholds and other criteria, to decide whether it's worth making an application, can be quite tricky as this isn't usually clearly stated on the UK Government websites.” (Carers and Care Experienced strand, survey respondent)

A few mentioned that they looked for information about benefits through social media. A small number of participants who mentioned finding information was easy were aware that some people could find difficulties of finding information online; for example people who do not have access to digital services, do not have computer skills or are elderly.

“If you have access to sort of like the internet and stuff like that and you’re sort of up to time, it’s pretty easy, you know, you can go online, you can research it, you can use these little calculator things that they have and all of that. But I think maybe for somebody who is maybe a bit elderly, they would prefer to use the phone...” (Carers and Care Experienced strand, single parent participant)

A few also said that due to the challenging sudden changes of their personal circumstances or their mental health conditions, they experienced more difficulty finding benefit information.

⁷ Please find more findings about difficulties of finding information on the ‘key barriers with the benefit system’ chapter.

“I was suffering mentally, I was dealing with a nasty break up, I am a single parent and found it very difficult to find out what I was entitled too. There are so many benefits all on different websites without the help I got I wouldn't have managed...” (Carers and Care Experienced strand, single parent participant)

Participants and respondents were asked about their communication preferences for making benefit applications. When asked to think about what channel they used in their most recent application, over half of survey respondents (56 per cent) said they applied online. A quarter (25 per cent) completed a paper application and the remaining respondents applied face-to-face (13 per cent) and by telephone (6 per cent) (see Table 6).

Table 6: Thinking about the most recent benefits application you have made, how did you apply? (n=16)

	Number of respondents	% of respondents
Online	9	56
Paper	4	25
Face-to-face	2	13
Telephone	1	6

Interview participants also have a diverse experience with most of them applying online and by paper. A few noted they applied in person with support of benefit staff. Most participants found the application processes difficult with a few noting that it was an easy process.

“There was nothing good about the [PIP] application process; nothing whatsoever. It is one of the most degrading, soul destroying processes that I have ever had to go through and, in the line of work that I do, I have seen a lot and done a lot, but that application process was really harrowing.” (End of Life strand, participant with terminal illness)

“The forms online have always been pretty simple and stuff, so nothing much to it, to be honest.” (End of Life strand, bereaved participant)

A few who mentioned that they found applying for benefits easy said they received support from advocacy organisations or benefit staff to complete the benefit forms.

“I had somebody sit with me while I did it online, but I'm not a very computer techy person so I think I would have struggled if I was trying to sit and do that on my own online.” (Carers and Care Experienced strand, young parent participant)

“The contact I then had with Social Security Scotland was then quite a quick process and that was really helpful. I would say the phone call and it was like a very short interview I had to have. It was for the Funeral Support payment. [...] The person I spoke to was really lovely. Like, really calm and supportive - I didn't really want to ask for help for the funeral. It was a huge thing to do, to ask for help and to go through that process.” (End of Life strand, bereaved participant)

Mixed views were noted concerning applying for benefits online. A small number mentioned that applying online was better way to apply than waiting in a telephone queue for hours.

“If you're comfortable enough to go online and fill out forms and stuff, great. But probably if you're doing it on the phone, be prepared to sort of wait a while to speak to people. Easier online, but hard to do without an iPad or computer. I found applying on the phone was difficult.” (Carers and Care experienced strand, single parent participant)

A few highlighted various further barriers to navigate the benefit system including lack of literacy skills or barriers to travel to benefit offices to get support and appointments.

“...also transport wise, getting to your local Benefit Office as well, that could be a problem, and maybe literacy skills if you're not able, or computer skills if you're not able to kind of navigate your way round an online application form that could be a problem.” (Carers and Care Experienced strand, single parent)

Support with navigating the benefit system

Many participants and respondents across the seldom heard groups reported a strong reliance on support workers from third sector organisations. They mentioned that they helped them with accessing various services, including the benefit system.

Third sector organisations gave them support for finding information about benefit entitlement, completing the applications and signposting to further services. The most common organisations participants and respondents emphasised as giving them support were those which work on, and advocate for the specific needs of the seldom heard groups.

I'd say my support worker and Streetwork in general. I've been off and on homeless a big part of my life, and Streetwork – they're a charity in Edinburgh and they're kind of genuine people, hands-on, the voice of us folk. They genuinely care about homeless people and getting them benefits if they're maybe not being treated fairly by the benefits system. They're my main source of information and the go-to guys if I need advice on what my actual rights are or what is the best thing to do in a

situation whether its regarding benefits or homelessness or whatever. [...] When you're in the claim process or pre-claim, as soon as you're on the benefits and you speak with a support group like Street Work and you explain your benefit situation, it's so much easier to get help. (Vulnerable Groups strand, homeless participant)

Terrence Higgins Trust. I'd normally phone my support worker and speak to him, and he's always available on the phone. [...] one of the support workers there helped me fill out the [PIP] form. We had to get stuff from my psychiatrist, my GP and my HIV consultant. And we submitted everything, and then I waited about six or seven weeks for a reply. And then it said I'd been awarded the care aspect, but not for mobility. But I was quite happy with that. (Vulnerable Groups strand, participant with HIV)

Some of the advocacy organisations they mentioned were: Who Cares Scotland, Simon Community Scotland, Cyrenians, Sacro, Shelter, Terrence Higgins Trust, BLESMA, Macmillan, MND Scotland, Maggie's Centre, Women's Aid, Funeral Link, among others. Many also mentioned that support workers from these organisations were essential support when they needed to attend health assessments and appeals. A few also mentioned that these workers spoke on their behalf with benefit staff.

"What had happened, because my partner had cancer, and they gave me a number for a welfare officer and she introduced me to benefits. My partner had been unwell for a long time, and so we knew Macmillan very well anyway, but when they knew he was dying, they really helped thinking about me and my future and things." [...] If it hadn't have been for [name] from the welfare service at Macmillan, I wouldn't have got by. A lovely woman, she put me in the right direction of who I should contact and what I should do really..." (End of Life strand, bereaved participant)

Some mentioned other organisations which support a wider range of people with financial and housing issues. Some organisations mentioned for their support with navigating the benefit system were Citizen Advice Bureaux (CAB), CFINE and StepChange.

"They [Citizen Advice staff] set it out for you and help you work out what you are entitled to, even things you wouldn't think of yourself. Any benefits I have had in the past, it's because they have let me know about something, and I wouldn't have known otherwise. [...] I trust Citizen's Advice to give me good advice, they have helped me. They are the main source of help, I don't really look on websites or anything. I speak to them." (Vulnerable groups strand, prisoner participant)

Some reported getting help from support workers from local authorities. A few also noted getting information from local support groups and foodbanks. Other mentioned their informal networks consisting of friends and family members as key contacts who provided them with information and support for benefit applications and processes.

“I just ask friends and family for advice. You get to find out what help is out there, what benefits to claim for that way. You just ask around, or people say ‘oh you have a kid you should claim for that now’. So yes, it’s all just through your contacts, and based on what they know.” (Vulnerable Groups strand, prisoner)

“It would have been through my social worker, through [my] aftercare worker, mainly just like through them kind of letting me know what’s out there...” (Carers and Care Experienced strand, care experienced participant)

Mixed views were identified in relation to support from benefit staff from DWP and Jobcentres. A few noted that they were helpful whereas several highlighted various negative experiences related with not being treated with respect and dignity.

“It’s not supportive; it’s not supportive at all [DWP staff]. You’ve got to beg - or at least that’s what I feel like. Begging for something that I’m entitled to. If I’m not entitled to it then fine; but if I am, why are you still treating me suspiciously, or like I’m a criminal?” (End of Life strand, participant living with a lifelong condition)

“I’ve got a work coach person through DWP, they phone me every 5-6 weeks to check in on me. He’s been very understanding, he’s the one that helped me sort this out with that money being taken off that shouldn’t have been.” (Vulnerable Groups strand, homeless participant)

The effects of the Coronavirus (COVID-19) pandemic on accessing the benefit system

Some participants and respondents were asked their views on the effects of the pandemic when accessing benefits and contacting benefit staff. Respondents were asked how easy it was to find out about the impact of the pandemic, furlough and self-isolation on benefits. Over half (54 per cent) said there were not sure, one in four (25 per cent) said it was easy and around one in five (21 per cent) noted it was not easy (see table 7).

Table 7: How easy is it to find out about the impact of coronavirus, furlough and self-isolation on benefits? (n=24)

	Number of respondents	% of respondents
Not sure	13	54
Quite/very easy	6	25
Not very easy/not easy at all	5	21

Survey respondents who provided some explanation of why it was not easy mainly noted confusion when having to look for information.

“There seems to be different grants that come out but often hear about them at short notice or when they are finished. The information on eligibility is confusing.” (Carers and Care Experienced strand, survey respondent)

When communicating by phone during the pandemic, a few interview participants experienced long waiting times for getting benefit information or for checking on the progress of their applications. Others also experienced being transferred directly to a telephone message explaining they were unable to receive their calls.

“...we still have a fair few people on ESA and getting someone on the phone before the pandemic was hard enough. You could be on hold for up to an hour before the pandemic, and now it’s got even harder.” (Vulnerable Groups strand, homeless participant)

A few participants highlighted the long waiting times not only with communication by phone; but also when waiting for the outcome of their applications or arranging phone appointments. In contrast, a couple of participants provided positive feedback with the option of being able to complete application forms or to provide evidence online.

“It’s difficult because I’ve been part of that during the whole Covid period largely, so it’s all been quite slow with my son’s PIP application...” (Carers and Care Experienced strand, single parent participant)

“The only thing I would say is that having the online forms this time has been really good. And, I think also, I know they [DWP/Social Security Scotland] are really busy during this time, and there will be less people available to deal with cases like funerals and things...” (End of Life strand, bereaved participant)

Some participants highlighted that they would abide by government’s rules and/or the use of personal protective equipment. One participant mentioned the financial advantage of not using public transport for face-to-face appointments.

“I think the fact that now you don’t have to do everything face to face, I sort of hope it stays that way because it saved a lot of money on public transport.” (Vulnerable Groups strand, homeless participant)

A few participants and respondents noted that as a result of the COVID-19 pandemic they were unable to communicate with benefit staff when they were looking for the reasons behind lengthy delays of benefit processes or changes.

“I have had multiple issues with money being stopped etc and it’s been very hard sorting and getting in touch because no one is at work”. (Carers and care experienced strand, survey respondent)

“It would have been nice for them to just say, ‘due to covid we’ve got a 6-month delay’, so that you’re not sitting there waiting, you know. And I was thinking any day now [...] any day now for months. And that’s just so long. So that was the main COVID thing for me. But it’s more frustration and wanting food and stuff ‘cause obviously the Universal Credit thing took ages as well. So, I was on very basic pay and my housing benefit didn’t cover my rent, so I was dipping into my money to pay for my rent and [sigh] it was just a bit of an ordeal. I felt like I was trapped for that period of time.” (Survivors of Abuse strand, survivor of abuse participant)

A small number of participants noted the impact of not accessing public spaces to use computers to complete requirements such as job searches as part of getting UC payments.

“They expect everyone to be online now, and you’re expected to spend 6 hours a day on the internet looking for work. [...] But you can’t with Covid just go to a library and log in there. I’d have to find one of my pals and find out if I could use a laptop at one of their houses.” (Vulnerable Groups strand, homeless participant)

Views on benefits being devolved to Scotland

Participants from the Vulnerable Groups strand were asked about their views of some benefits being transferred from DWP to Social Security Scotland. A few participants were not aware of the changes in the administration of some benefits. Mixed views were conveyed when being told about the changes.

A few thought this change will affect positively and they were hopeful that clients will have more help when accessing benefits.

“I was looking at the Scottish Welfare Fund. I think it is brilliant, I really wish the whole thing would be devolved really, because I have the impression that Scottish Government and the majority of parties in Scotland want the system to be quite equitable.” (Vulnerable Groups strand, participant with HIV)

“I’ve read something recently about PIP being moved under the Scottish legislation rather than the UK, the Scottish Independence Payment or something. I’d hope that might be slightly better than the UK experience because lots of our guys apply for PIP and don’t get it, mainly because most mental health conditions are invisible [...] Mental health doesn’t seem to be taken into account. [...] I would hope at least that they would make sure that everybody stays on their current payment until they can

be reassessed and I'd hope they won't penalise anybody." (Vulnerable Groups strand, homeless participant)

"No, I wasn't aware there was any changes with DWP and Social Security Scotland. I had no idea anything was changing, who decides. I think it can only be a good thing if Scotland can decide how we do it." (Vulnerable Groups strand, participant with HIV)

A small number of participants mentioned that significant changes in the benefit system were unlikely as Social Security Scotland would still depend on the UK government to make changes on benefits. One participant thought the delivery of devolved benefits would be worse because Social Security Scotland will need time to learn to implement and delivery them.

"I feel that as long as England's in charge, there's always going to be stumbling blocks in between cos it's going from London to Edinburgh and then to us. If it was direct, one-to-one... But right now, it's got to go through two governments." (Vulnerable Groups strand, homeless participant)

"Things moving from UK to Scotland I don't think things will get any better. It's just a different outfit doing the same thing. It will probably get worse because they have to find their feet with it. Changes to benefits over the years have just made them harder and harder." (Vulnerable Groups strand, homeless participant)

A few participants raised the following concerns and fears regarding the transfer of some benefits to Scotland: data security, the need to reapplying and the decrease of their current payments.

"The only thing I'd worry about would be because my award runs out May 2023; it got extended for a year because of the pandemic. My thing would be when it does go over to Social Security Scotland, would I need to reapply, or will it be automatically transferred over? That would be the sort of thing I'd be worried about." (Vulnerable Groups strand, participant with HIV)

Key barriers to the benefit system

Common barriers and challenges were experienced across seldom heard groups. They are discussed below.

Difficulties finding information

Several participants and respondents highlighted the difficulty of finding information about what benefits they may be entitled. Some mentioned that this resulted in avoiding starting claims, missing out or delaying access to the benefits there were eligible for.

“I didn’t claim PIP until 6 months after I could. [...] I should really have been told what I was entitled to.” (End of Life strand, living with a lifelong condition participant)

“I don’t think it’s that easy like to figure out like what to do or who you could speak to if I need to especially because I feel like it’s always like; well I feel like it’s almost like in the shadows [...] I’d look like through social media or like through the Internet or something like, but you know, it is quite challenging to figure that out, [...] I think it’s quite difficult from my experience. I think it’s really difficult because they say there’s so much out there, but at the same time, personally me right now, I’ve not managed to find any benefits that I’d be entitled to right now...” (Carers and Care Experienced strand, care experienced participant)

For many the information was unclear, confusing, and contradictory. They mentioned there are several sources of information, but it is not streamlined nor clear. A small number of participants thought the information was concealed and withheld in purpose.

“At the moment it is too hard to find out what you are entitled too, I checked online and there was like three or four things that was telling me all different things, so, it’s not easy I wouldn’t say. I reckon a lot of people would give up if they didn’t have any support.” (Carers and Care Experienced strand, Kinship/foster carer and adoptive parent participant)

Many thought that benefit staff from DWP and Jobcentres were not transparent about providing information about potential eligible benefits to clients. They said the staff usually withhold information to avoid people claiming benefits they are entitled to.

“The Jobcentre withhold information from you, they don’t tell you what you are entitled too. You have to find out through your own sources, through word of mouth or someone else helping you. I had it once where a social worker advised me about

a leaflet that had all the up-to-date benefits information in it, they told me I'd have to ask for it at the Jobcentre. I asked for it and the person behind the counter went round the back and got it for me. And I asked them why they didn't have them sitting out at the counter so everyone could pick one up and see that up-to-date information. They just ignored that comment. Really, it's because they don't want to advertise what people are entitled too. Even when they have the information, they are hiding it away. That made me very upset on behalf of other people who weren't given a tip to get that booklet. (Vulnerable Groups strand, prisoner participant)

A few highlighted the complexity of navigating government websites. Related to this, some reported the challenges to find the correct information from official channels which in some cases were given conflicting information.

"I think on the Government's website they could maybe like [...] explain it a bit more simpler for people who maybe don't understand what some of the stuff they've got written on the website means, because it can be quite confusing to figure out what you could be entitled to, and I think some people don't apply for some stuff because they don't think they would be entitled to it, when they actually are." (Carers and Care Experienced strand, young parent participant)

"When I was told about Housing Benefit I checked online and there was like three or four things that was telling me all different things, so aye, it's not easy I wouldn't say." (Carers and Care Experienced strand, single parent participant)

A small number of participants mentioned the lack of a joined-up approach of government services to signpost and provide benefit information to clients. This caused them to retell their personal circumstances several times before finding the right person with the correct information.

"I think it's quite difficult [to find information] actually! I think it's, even Universal Credit, although it's a simplified system, it's actually, it's not really that simple, and I think then when you're adding in like Disability Benefits, Child Benefits and then possible passporting so like Uniform Grants or Free School Meals; it's really actually quite a complex system and I don't think that that's really clear to people." (Carers and Care Experienced strand, kinship/foster carer and adoptive parent participant)

A small number of participants reported they were not told about their eligibility for passported benefits and they only found out about them circumstantially. Many said they knew about their eligibility to benefits by chance. One participant thought that being able to navigate benefit information will depend on the level of literacy of clients.

“I missed out on a pregnancy payment I think it was for 3 payments of £250. I didn’t know about it and when I found out about it, I was too late to apply.” (Carers and Care Experienced strand, single parent participant)

As a result, many participants mentioned that they only knew about possible entitlement to certain benefits from third sector organisations, council support workers or their support networks.

“If Citizens’ Advice hadn’t helped me, I wouldn’t have known that I would have qualified for this severe disability premium and all these other things that they don’t tell you. [...] Between CAB and my own research and finding what the points system means and how they’re supposed to be basing the assessments, you wouldn’t have a clue. [...] they didn’t inform me that I would qualify for this severe disability premium. It was Citizens’ Advice who informed me of that and we had to apply for that. I get it back paid, and also the cold weather payment, which I apparently qualified for.” (Survivors of Abuse strand, survivor of abuse participant)

Complexity of application forms

Many participants and respondents felt that the application forms were lengthy and complicated. The wording of the applications was considered complex and not user friendly. A few thought how because of this, application forms can be difficult to complete, especially for people with literacy issues. Some mentioned that the questions were too prescriptive and repetitive and they did not allow them to capture the nature of their health conditions or their particular circumstances. Others felt that the questions were designed to avoid successful claims.

“I think the way that the questions are worded it’s as if they’re trying not to award you the money, if you want my honest answer. The questions are very ambiguous, and they’re not really written in a way that lets you explain your whole situation - it’s patchy.” (End of Life strand, participant with a terminal illness)

“I am a relatively intelligent individual, but looking at that form [PIP application], to fill it in, I can only say that I feel heart sorry for individuals who maybe don’t have the level of intelligence that I have. I completed that form, and I found it myself, having only recently been diagnosed, an exceptionally distressing thing to do because you have to write down exactly what you can and cannot do in graphic detail to effectively justify why you’re asking for government aid and assistance. [...] what can only be said was a harrowing experience of completing this monumental form to detail what I could and couldn’t do and enclosing all of the additional information that they requested from me was a mammoth task...” (End of Life strand, participant with a terminal illness)

“I suppose, I’ve been fortunate in that I’ve got a good standard of education and so has my wife and that has helped us with the [application] process [for PIP]. [...] But individuals who are maybe not as literate as ourselves, that would be concerning. I notice that there is a lot of duplication in the PIP [application] form, and I know that it’s designed to ensure that you are eligible, and to confirm your answers are accurate - asking the same questions in a different way. But, for a lot of people, that can’t be easy.” (End of Life strand, participant living with a lifelong condition)

Many commented that they could have not completed the application forms without help, mainly from support organisations. A small number of participants thought that completing forms with these organisations would mean that the applications were more likely to be accepted.

“I usually go to Citizen’s Advice because I feel that, even though I can complete the forms myself, that [having it checked by Citizens Advice] usually rubber stamps it. I feel that if you just fill in the forms yourself, even though they’re probably fine, if you have it checked by Citizen’s Advice or approved by them then they [DWP staff] accept it without question.” (End of Life strand, participant living with a lifelong condition)

A few mentioned that some people are discouraged from applying for benefits due to the complexity and the length of the forms. A small number of participants also highlighted that due to these complex applications, they commonly felt unsure about being eligible to claim benefits.

“I think some of the forms you get when you’re claiming a benefit, there’s questions in there that you need a PhD to understand. And I think they’re there to trick you, and I don’t think that’s very fair. You look at the form, and it’s over 100 pages, and if you don’t understand the question it’s asking you, you’re stuck. That’s why you need help. It’s not very easy.” (End of Life strand, participant with HIV)

“I’ve always struggled with all the forms, asking myself ‘Should I be claiming, or should I not be claiming’ and it’s just the inference that anyone who is claiming from the government is cheating the system” (End of Life strand, participant living with a lifelong condition)

A few participants were critical about being asked to complete new applications to continue receiving their PIP award as their health circumstances have not changed or they were likely to deteriorate due to their progressive nature of their health conditions.

“I went through the equivalent of filling in a brand-new application form which involved her [staff member on the phone] asking me a series of questions about the details of the condition, the level of disability, what drugs I take, what effect they

may have. All of that - it was about 45 minutes. [...] then, I got a 40-page form in the post and spent hours filling it in. It came in hard copy, all of which was an entirely pointless exercise - very time consuming and deeply offensive. It's almost as if they've deleted your history and everything they already know [...] I don't anger easily, but one of the worst experiences I have had, because it was so crass, was the call with them to review my continued PIP when I am clearly still terminal and am always going to be. They are trying to make you justify help on the basis of an illness that they already know is serious and is terminal and nobody wants to be in that situation, but that just didn't seem to register with them." (End of Life strand, participant living with a lifelong condition)

A small number of participants questioned having only the option of paper format for the PIP/DLA applications as some clients will find challenging to write due to the nature of some health conditions. They suggested that an online format should be an option.

"...for someone who has motor neurone disease, sending a form out where you have to write in it is impractical because obviously the deterioration in your fine motor skills means you can't write. So, why, for these people [with MND], why you can't have a form online is beyond me. In fact, there are no alternative formats, I don't think." (End of Life strand, participant with a terminal illness)

Challenges when accessing the benefit system online

Many highlighted the challenges related with applying for benefits online. These include not having access to a computer or a smartphone, not knowing how to use them, and not having access to internet. Some participants also thought that people who are not computer literate may feel embarrassed and struggle to get help.

"As it is all online, I struggle to understand and apply for benefits on my own." (Carers and Care Experienced strand, survey respondent)

"...people do not want to admit when they aren't good for technology. I know people that just hide that they can't work it, they don't ask for help. It might even be that they have problems reading and writing too, so even more issues than not working the computer. When you move things to be online forms and such you need to get in all the support to help people as part of the change." (Vulnerable Groups strand, prisoner participant)

Some highlighted the difficulties of only having the option to apply to benefits online, specifically stressing the challenges with Universal Credit processes. A few participants highlighted the various problems vulnerable people face when the only option to get benefits - like UC - was through digital services. They mentioned that

this can result in excluding many people from accessing benefits they are entitled to.

“Simple basic things like email addresses, lots of our clients are so chaotic that they can’t have a mobile phone for more than a day without selling it or losing it. So, expecting people to have access to the internet and set up an email address and then liaise with job workers on Universal Credit, I find is a bit unrealistic to be honest. Most of our clients will give us their logins and we’ll check it and tell them what they need to do, because otherwise they’d fall off their benefits virtually every month. I don’t think it’s really workable to have all those things in place. [...] I think UC could be looked at and realise that maybe not all people have access to technology or if you’re homeless, the internet. To assume everyone can do that online I think is a huge problem.” (Vulnerable Groups strand, homeless participant)

Many who did not have a support network or access to digital services highlighted that they knew about benefits only through their support workers or informal networks. They also relied on them to help them with application processes due to their lack of computer literacy. A small number of participants mentioned that they could not have been able to complete applications without help due to learning difficulties such as dyslexia.

“The fact that you had to apply for that benefit [UC] online. I feel that, for someone with dyslexia, that’s a bit harder. So, for most of my stuff, it was my daughter who did it online. So, someone who had not got a family, they’d be struggling to understand. You know, you’re not allowed to phone up and apply for it over the phone or, you know, go into the job centre and apply for it. You just have to fill it all in online.” (End of Life strand, bereaved participant)

“They have been helping me with that in the Hub here a bit [Simon Community], trying to email or look at things and find out what the latest is. Because I’m a wee bit dyslexic so that helps. I’m okay at reading and counting but spelling and that I’m not. So, it helps to have someone to read over. And then computers I’m shit at too, so again they help me with that in here.” (Vulnerable groups strand, homeless participant)

Gathering information and evidence for application processes

Some participants reported various challenges for getting personal information or evidence required as part of their application processes.

A few participants from the carers and care experienced groups highlighted their difficulties to gather personal information and evidence they needed to apply for benefits. Challenges included providing background information for care experienced people or benefit history for an adopted child.

“I thought it [application process] was quite, you know; quite difficult because there’s so much of it and there’s so much information that they need and they need to know whys and hows and wheres and a lot of your background and [...] luckily for me I’m aware of my background and my details and stuff, but there are a lot of .care experienced children that I know that maybe don’t have a greater understanding that I do, so it would be quite difficult for them to access it themselves.” (Carers and Care Experienced strand, care experienced participant)

“...adopting the girls at the age they were, and even then it’s difficult to do because when you do apply for things like that [child benefit], you have to give their history. Now, in an adoptive situation, especially as ours was, we’re not told which foster parents, if any, or their birth parents, have applied for that [...] there’s things that we can’t answer as adopted parents, that folk can’t get, that we simply can’t answer the question, which makes it a little bit more tricky.” (Carers and Care Experienced strand, kinship/foster carer and adoptive parent participant)

Some participants from the vulnerable groups, in particular those who experienced homelessness or were in custody, highlighted challenges because they did not have a permanent address, a bank account or an identity document to start and follow up benefit applications. Furthermore, a small number of participants who experienced homelessness reported delays on their benefit payments because they were changing their address frequently.

“When I got release from prison, they were just introducing UC, that was the hard part. A lot of people come out of situations like that or living on the streets, they’re not gonna have ID or papers like that. Lack of ID’s a big problem for a lot of people. If you don’t have a driving license or a passport, then you’re pretty much screwed.” (Vulnerable Groups strand, homeless participant)

“What I found with the benefits system it was like, ‘Give us your address or your email address’ and I said I didn’t have an address, ‘I’m homeless’. And they said ‘Okay, well then give us your email address’ and even that I had to ask the library if it was alright to set up an account. This was just one person’s journey to get the money I was entitled to and it took almost a year to get it all set up. It’s not a glitch, the whole thing’s screwed.” (Vulnerable Groups strand, homeless participant)

A few participants noted challenges to obtain evidence as part of their application. A couple of participants felt that they were frequently asked to provide further evidence during the application process when they thought they already provided all the necessary evidence for their claim.

“...in the background they’re constantly reviewing everything and playing a little bit of catch up or something’s going on. Thinking, like you say you’re on that page I’m on and I’m making the right track now - everything is fine. And then something

comes along or they've found another thing that you need to provide and you go backwards. (Survivors of Abuse strand, survivor of abuse participant)

Some noted that getting evidence related to mental health conditions was difficult. Related to this, a small number of participants felt that the medical evidence they provided was not recognised as much as it should be as part of their medical assessments.

"...when you're working with people with mental ill health, to try and get that evidence, I think it's a really misunderstood area around the disability benefits in general..." (Carers and Care Experienced strand, kinship/foster carer and adoptive parent participant)

"All the time I've been having to 'prove' I have a mental health condition. You have to repeat yourself to different people, and that's even with my doctor, who has known me for years, telling them. They should trust him as a professional and an expert. Whereas the benefits people getting in touch with me don't have any medical expertise." (Vulnerable Groups strand, prisoner participant)

A couple of participants mentioned the short timescales given for the turnaround of the evidence as part of their benefit applications. Others highlighted that it took them a long time to collate several pieces of evidence to start completing the application forms.

"The other thing is the timescales. If you fill out the form, they only give you a week to send in your documentation which is a very short period 'cos, by the time you get through to them, and they write the letter and send it over. And it's the same with the GP." (Vulnerable Groups strand, participant with HIV)

"It's a 70 + page paper form which requires loads of evidence. It took me over a year to get round to applying and finding all the evidence." (Carers and Care Experienced strand, survey respondent)

Health assessments

Many participants experienced stress and humiliation when attending health assessments. Some thought the process of medical assessments is dehumanising and it is carried out in a distrustful atmosphere.

"I think when you go for assessments with the DWP, they do treat you differently, they don't treat you like a person. They do speak down to you and, with some of the health issues I've got, you really don't need that. Firing questions at you and not giving you time to answer. They don't treat you like a human being." (Vulnerable Groups strand, participant with HIV)

“It is barbaric and it has caused me a number of dark moments of upset, grief, crying, rage and anger at the entire system and what it is forcing me to do. It is utterly degrading...” (End of Life strand, participant with terminal illness)

Others noted the questions during the assessment were closed questions based on a tick-box exercise with no room to account for fluctuating health conditions, in particular mental health conditions. A few thought the assessments were purposefully designed to make it hard to get successful benefit claims.

“I’d say the overall scenario is that you’re coming at it [treated] with total mistrust. From the very start you’re having to prove every single thing, and as someone with an actual disability, it is quite demoralising. If you’ve got access to people’s medical records, it shouldn’t be advisors even though it’s been a few days training online. That’s the message being given to the public: we’re here to make sure you get cut off. [...] I believe it’s meant to be confusing; I don’t think it’s a mistake. I think they specifically try to confuse you to make it seem like you’ve failed some sort of test and then they can cut off your benefits.” (Vulnerable Groups strand, homeless participant)

Some participants felt that the views and comments of assessors were subjective. They thought that the outcomes of the benefit award decisions were the result of chance, mainly depending on the subjective comments of the assigned assessor.

“So many people have received decisions that are just not fair and that’s a real downside to me. It’s a lack of consistency even for people living with the same conditions.” (End of Life strand, participant living with a lifelong condition)

Others noted that the medical assessment reports gave inaccurate accounts of their health conditions. They said the reports did not reflect correctly what was said during the assessment nor how the evidence provided was considered for the outcome of the award.

“They send you a copy of the assessor’s comments, and you see what they’ve said. And loads of it was a pack of lies. Saying I’d said stuff that I didn’t say and saying that the assessment took 40 minutes when it only took 20 minutes.” (Vulnerable Groups strand, participant with HIV)

“It doesn’t explain their reasoning behind their decision, so they’ll say I’ve decided that you don’t need help, or your daughter doesn’t need help with X, Y, Z, but it doesn’t really explain how they’ve come to that conclusion [...] there’s no sense of them actually looking at all the evidence in front of them and not being biased.” (Carers and Care Experienced strand, kinship/foster carer and adoptive parent participant)

Some participants noted that attending the assessment with support or advocacy workers helped them to be treated more fairly by assessors. They thought with advocacy support during the assessment they were more likely to get successful claims.

“BLESMA have supported people who have got their benefits taken off them, told to work, but then they have appealed and got them back. [...] I’ve been told when I do get my PIP assessment BLESMA will send someone to accompany me, another regional representative. Charities are having to get involved and supervise things in order to help people be treated fairly.” (Vulnerable Groups strand, veteran participant)

“I’d get a letter saying my claim was about to end. So upon getting that, I’d just get in touch with my support worker and the disability rights group. I’d get my doctor to write out the documentation to show that this is real life: there’s a MRI, CT scan, all the medical documents. Then when it comes to going to the means test, just to make sure I had somebody there to witness what was going on in the office. At least that way it doesn’t matter what happened in that office. I find that when you bring someone else they ken they cannae demoralise you.” (Vulnerable Groups strand, homeless participant)

A few were critical about the frequency of health reviews for some long-term health conditions unlikely to change. A small number mentioned that they requested in home visits but those were denied.

“Now, surely, if you got DLA for life, you should get PIP for life instead of having to apply yearly or three yearly. Some people are never gonna change, like me, so surely they can put something on [their system] that notifies them that this person is not going to get any better. You know, because every time I have to relive my horrific experience again and again and that feels like they’re punishing me for having an accident [...] I’ve seen doctors, I’ve seen panels - it’s obvious that I’m seriously disabled and that’s never ever going to change.” (End of Life strand, participant living with a lifelong condition)

“When I did the form last time, I asked for a home-visit ’cos I said it makes me really uncomfortable [going in], but they said no, if you don’t come in you get your money cut off.” (Vulnerable Groups strand, participant with HIV)

Stigma and distrust from the benefit system

Many participants felt discriminated and stigmatised against when interacting with benefit staff and when applying for benefits with the DWP and JCP. They thought

the system treats clients as ‘scroungers’ or criminals trying to commit fraud by using the benefit system.

“It’s a completely different thing dealing with benefits. Everything becomes harsh and rude and undignified. You’re made to feel like you’re scum because you’re needing help. [...] The whole process for me, from the get-go, as soon as you enter that Jobcentre, the whole thing is set up for you to fail. The whole thing’s just a run-around, a demoralising thing.” (Vulnerable Groups strand, homeless participant)

“Makes you feel that you are not applying for a benefit, you are getting a reward for being good. That’s how it feels. I understand some people milk the system, I’ve seen people to in the past who have got away with doing that. But the system sets you up to be adversarial.” (Vulnerable Groups Strand, participant with HIV)

Some participants said they felt the whole culture of the benefit system is underpinned by distrust and suspicion towards the client. They felt frequently judged for relying on benefits and not being on paid work. Some felt that their individual circumstances were not considered as an explanation for needing financial support. Many thought the benefit processes were a dehumanising experience.

“I think if you’re on benefits you’re probably being looked down on. You’re just seen as not even a human sometimes; the way people treat you. They don’t care, it’s like they look at you like well you chose to go and get pregnant and not have a job and things like that. Nobody cares that you might have been working your whole life and things have happened that are out of your control. It’s just seen as well you’re on benefits, you’re not helping the economy, you’re not helping anything, you’re just sponging off everyone that works.” (Carers and Care Experienced strand, single parent participant)

“I feel degraded, I’d rather they were honest [...] And that’s affecting my mental health and it’s affecting me. Sometimes I just think I could go get dodgy Valium and that, I don’t want to do that. I just want help to do things properly.” (Vulnerable Groups strand, homeless participant)

This negative perception towards the benefit system made many participants anxious and stressed when having to carry out benefit processes. A few mentioned that going through these processes exacerbates their mental health conditions. A small number of participants would avoid in person communication with benefit staff as a result of how they made them feel.

“They [benefit staff] don’t know your history or your medical history, but they’re judging you. So you’ve got a doctor saying you’re unfit to work, they fill out a form,

and then they turn round to say you are fit to work. [...] I don't like face-to-face interviews because the person assessing you, they're not very nice and my anxiety shoots through the roof. The last time, I came out and I was shaking, my heart was beating really fast. They don't treat you like a person at all, they have no communication skills." (Vulnerable Groups, participant with HIV)

"I am on medication for anxiety and so something like this [application process] obviously makes that a lot worse. And, I don't think they take things like stress and depression and anxiety into account. [...] it's really stressful and I'm not sure they're really thinking about that when you speak to them [DWP staff]." (End of Life strand, participant with terminal illness)

Some felt distrust and suspicion towards benefit staff. They thought they were not providing all the benefit information about what they could be eligible for. Others were afraid of making any mistake during the benefit process as they felt that would result in their claim to be unsuccessful.

"When I've gotten advice on the past, say from the Jobcentre, I've felt like people are trying to lead you. Trust means so much, you need to trust the people helping you. When I have been given advice from the Jobcentre you feel that they are trying to tell you as little as possible to help you..." (Vulnerable Groups strand, prisoner participant)

Waiting times, benefit changes and financial hardship

Several participants gave accounts of the lengthy waiting times for various benefit processes. They reported how these waiting times made them experience financial hardship.

Many participants who had experiences with UC processes highlighted that the waiting times for their first payments were too long and impacted negatively on their finances. A small number commented the adverse consequences of asking for advance payments as they had to pay them back when receiving the next payments. Few others also noted the lengthy wait times for receiving the new UC payment once they reported changes in their circumstances. They stated feeling stressed or worried because of these waiting periods.

"I was reeling from losing my job and then because of my health deteriorating it made sense to move back to [place] and back to where I had family near. And the day I moved back I put in a Universal Credit application. If I didn't have the support from my parents I would have suffered because that 5 week wait is shocking." (Vulnerable Groups strand, participant with HIV)

"...they [benefit staff] say to you 'do you want a loan to tide you over'. But of course, but then you are paying the loan back. They take it right back off you [...] It was just

changing addresses all the time. Sometimes your benefit was late because they were updating your details again, and then the payment was late. [...] It was hard to budget and buy things. (Vulnerable Groups strand, homeless participant)

Some participants also experienced lengthy waiting times for getting award decisions, mostly for some disability related benefits like PIP or DLA. They also highlighted the lack of updates during the waiting period and the financial uncertainty that it caused them. A small number of participants stressed the pressure of time against their particular circumstances such as living with a terminal illness or needing to pay for the funeral of their loved ones.

“For the funeral payment, I’m sure I did it over the phone. That was okay, but again it was the time. I think I got the money on the actual day of her funeral and so it’s a worry. I didn’t have money to pay the funeral director. I paid them what I could, like £300 on the day, but it’s a long wait if you don’t know what else you’re going to get. And, I remember, on the day of the funeral, I handed £300 to the funeral director and he was saying, ‘you don’t need to worry about that just now’, but I was.” (End of Life strand, bereaved participant)

“... the way in which the DWP have dealt with my claim [...] is abhorrent and barbaric. We should not, when we have this diagnosis, given the timescales that we are given, we should not have to wait 6 months for the DWP to get their arses in gear, to be frank. We should not have to be chasing them up, going to our MSP and Citizens Advice Bureau. We should not have to lodge complaints; we should not have to be on the phone begging people to show some humanity in processing this claim.” (End of Life strand, participant with terminal illness)

Some participants also negatively perceived the lack of any updates about various benefit processes. They were not made aware of waiting and specific leading times or they did not receive any acknowledgment from agencies about receiving their applications or new evidence they provided as part of their claim. As a result, a few of them were proactively trying to communicate with the DWP or JCP without success.

“The PIP benefit took a long time; it was a paper application and took over five months before I got any sort of response. I tried to call and was put on hold for over an hour quite a few times. There is just no communication.” (Carers and Care Experienced strand, single parent participant)

“...one thing that would help people would be to know how long changeovers are going to take. If it’s going to take six months, you need to let people know. The DWP must have known how long it was going to take them to get through all of the applications and conversions, and to me they could have communicated that better.” (End of Life strand, participant living with a lifelong condition)

Many participants reported that the lengthy waiting times for getting payments and receiving award decisions caused them financial difficulties such as a needing to use foodbanks, borrowing money and relying on their family networks to get by.

“Once you get your benefits, you got to sit and wait weeks you know. So that’s a worry. I had to use the foodbank, because I didn’t have any money for food.”
(Survivors of Abuse strand, survivor of abuse participant)

“I don’t feel like the amount is enough even to cover the basics; food, bills and clothes. I would get nearer the end of the month and find we had run out of hot water, I couldn’t put more money in the electric meter.” (Vulnerable Groups strand, prisoner participant)

Other participants mentioned experiences of benefit overpayments, sanctions, or lack of knowledge about benefit eligibility as factors which caused them financial hardship.

“... [difficulties due to overpayment] it basically means I have to rely on, to borrow money from my family until I can afford to pay rent, and then I have to pay them back. So, I think I’m in a very fortunate position that my family can lend me money. I know a lot of people don’t have that.” (Carers and Care Experienced strand, single parent participant)

“... I’m like trying to get help from my partners and my family and like foodbanks and things like that because we don’t know what’s out there [benefits]. It’s not really kind of highlighted or anything.” (Carers and Care Experienced strand, care experienced participant)

“I met someone who’s been sanctioned for three years and he’s got two years left and I just said, ‘How do you survive?’ He’s just living off foodbanks and charities.”
(Vulnerable Groups strand, homeless)

Many participants expressed their views in relation to the value of benefit payments being too low, and not matching the cost of living. Others thought the value of the payments were low because it deters people to rely on benefits. A few participants who had experiences of being in custody mentioned that they felt their basic needs such as housing and food were better covered when being in jail.

“Since Universal credit was introduced the amount of money everyone gets has gone down. £40 reduction in a month is huge for people. That means £20 less a fortnight to spend on things like your bills. And you end up depending on foodbanks when you didn’t used to. The dole doesn’t cover the amount things cost.”
(Vulnerable Groups strand, prisoner participant)

“You end up thinking to yourself, well I’d be better off in the jail than I am now. Because you have a roof over you and a three-course meal. I wake up and think about the stress and the struggle and think I’d be better off in there. [...] They expect you to live off £7 a day or something to cover everything. I couldn’t cover my bills with my benefits, I ended up on the street.” (Vulnerable Groups strand, homeless participant)

“They [benefit systems] haven’t thought about benefit amounts to cover the costs of things now. [...] People I know are having to make choices on feeding their family or paying for their housing, they pick feeding the family, but then if you end up evicted it ends up even worse for your family. I know a lot of people like that where I’m from. People are having to make tough choices every day.” (Vulnerable Groups strand, prisoner participant)

Enablers and views on improvement of the benefit system

Positive experiences (enablers) around the benefit system were identified through the interviews and the online survey. Some participants shared their thoughts on how the system can be improved. Key enablers and views on improvement are outlined below.

Multi-channel access

Across the Seldom Heard groups, suggestions of having a range of choices to access information, to apply to benefits and to get support were conveyed. Many thought the provision of various channels of communication would suit the different needs, circumstances, and preferences of clients.

When asked about their preferences for getting information about benefits, survey respondents selected various methods: less than two thirds (63 per cent) said they would want to get such information online, a third (33 per cent) wanted the option of written information (such as leaflets or flyers). Similar number of respondents (21 per cent) also wanted to get information from organisation and professionals, Jobcentre Plus, and friends and family (see Table 8).

Table 8: How would you prefer to get information about any benefits you are entitled to in the future? [select all that apply] (n=24)

	Number	% of respondents
Online	15	63
Written information - written leaflets, flyers, etc	8	33
Friends/family	5	21
Other organisations/ professionals	5	21
Jobcentre Plus	5	21
Newspapers/magazines	2	8

When asked how they would like to apply for benefits (Table 9), the majority (71 per cent) said that they would prefer online, a quarter (25 per cent), said they would like to apply face-to-face with the remaining 4 per cent favouring paper methods.

Table 9: What would be your preferred way to apply for benefits in future? (n=24)

	Number of respondents	% of respondents
Online	17	71
Face-to-face	6	25
Paper	1	4

Similarly, interview participants had a range of preferences for how to access information, how to apply for benefits and how to get support. These included: online, written information, telephone, and face to face communication. They were also aware of the various preferences of other clients. Many also explained their communication needs resulted from their individual personal and health circumstances.

“The system needs to account for differences in circumstances, and personality, and education to be fair really.” (Vulnerable Groups strand, participant with HIV)

“Everything should be done by letter because a lot of individuals are of an age, especially above 50, where they are probably more suited to receiving written information instead of IT information, where they have to have a smart phone or something like that.” (End of Life strand, participant living with a lifelong condition)

“... [finding out about benefits] it depends on age, young people are all on computers and their phones and all their IT stuff, so certainly IT, but I still think like the older generation are more into like something to read and stuff, paper docs [...] different methods for different groups.” (Carers and Care Experienced strand, kinship/foster carer and adoptive parent participant)

A small number of participants also highlighted that it would be useful to advertise information using various communication methods - such as TV adverts - to increase awareness and take-up of benefits. The provision of a helpline with all the information was also mentioned by a few.

Many participants and respondents suggested the provision of written information in the form of leaflets, booklets, posters and pamphlets by key workers such as social workers, health visitors, and housing officers. They also recommended to offer these in various places such as GP surgeries, NHS services, libraries, local authorities and benefit offices. Many wanted the written information to be delivered to where they lived.

“I think, when you get all of the information from the hospital about the medical side of things, there maybe could also be information that they give you about financial assistance. That would definitely help. Because that is something that could make a real difference to people.” (End of Life strand, bereaved participant)

“I like picking up a flyer so you can take home and read when you have more time. Maybe a flyer or poster in the library and at the doctors would be good too. [...] maybe the midwife. Maybe she could come with like a pack of all the information on benefits that are out there and not having hundreds of places online to look for stuff.” (Carers and Care Experienced strand, single parent participant)

Some suggested offering information online using a dedicated and specialised website about benefits. Many stated the provision of information in government websites and social media platforms in a simple and clear format. Some preferred to complete applications and various benefit processes online. A few suggested giving information and support using an online chat function. Some recommended receiving benefit information and updates of applications by emails.

“...having an email or an online account might have been good for me, to read over things at night.” (Carers and Care Experienced strand, single parent participant)

“Everything on one website would help lots of people, makes it much easier. Not having hundreds of different places online! You know an online calculator would be a good idea. Something online that can show you what you are entitled too if things change instead of waiting for a letter telling you what’s going on.” (Carers and Care Experienced strand, kinship/foster carer and adoptive parent participant)

A small number of participants gave suggestions for people who are digitally excluded to the online benefit system. A few recommended offering digital devices with internet services to them. Others suggested to provide clients with support workers to train clients to use technology so they could use the benefit system online.

“Why not send specialist digital inclusion workers into hostels two or three times a week?” (Vulnerable Groups strand, homeless participant)

Some mentioned the telephone and texts as the main channel of communication for information and application processes. Others highlighted the need for face-to-face communication including video calls and home visits. They said in person communication helped to express their particular circumstances better rather than using paper forms. A few reported preferences to attend government offices as opposed to having staff visiting at their home.

“I’m always more comfortable over the phone because of my mental health. If I have to go in face to an appointment, I need to get someone to go with me to keep me calm. A friend or someone because I have mental health problems. On the phone I can just talk.” (Vulnerable Groups strand, prisoner participant)

“Someone with mental health or mobility issues, obviously a house visit would be more beneficial to them...” (Vulnerable Groups strand, homeless participant)

“I’m a big one for like face to face contact because anybody could be typing behind a screen [...] generally speaking, face to face is so much easier and I think you would need a lot less information about the person if you actually just spoke to them face to face, or through a Facetime call or things like that, I think it would make the process a lot easier.” (Carers and Care Experienced strand, care experienced participant)

Comprehensive and streamlined information

Many participants highlighted the importance to provide information that is accessible, easy to read, clear and in plain English. They said the information should contain comprehensive information about eligibility, levels of funding and various application processes. A few said that the information should also include benefit eligibility based on age range and specific circumstances.

“...just having clear information available and making sure that things like websites and any publicity materials are clear and easily accessible. [...] So, I think having information that’s clear about who’s eligible, that’s clear about what levels of funding are available, and on what basis I suppose would be good, you know, as with anything just being clear and making sure that the information is written in plain English and stuff like that would be good. (Carers and Care Experienced strand, kinship/foster carer and adoptive parent participant)

“... explain it a bit more simpler for people who maybe don’t understand what some of the stuff they’ve got written on the website means, because it can be quite confusing to figure out what you could be entitled to, and I think some people don’t apply for some stuff because they don’t think they would be entitled to it, when they actually are.” (Carers and Care Experienced strand, young parent participant)

Many suggested the provision of a dedicated point of contact which focuses on giving all the information and support about benefits. This dedicated staff can give help to navigate the benefit system and signpost services that can be useful to the client and their particular circumstances.

This dedicated service could be in the form of a ‘one-stop shop’, ‘drop-in’ service or ‘benefit’ ambassadors. A small number of people suggested this staff to be in benefit offices or key services that they usually attend such as local communities, hospitals, etc.

“It would be good if all the information on benefits were in one place, like a one stop shop.” (Carers and Care Experienced strand, care experienced participant)

“Perhaps having benefits ambassadors. People that can support new claimants into the system, help people if they are not digitally aware. [...] But I think that having some side of having a person help you navigate through. [...] Really simple questions, plain English, really efficient, listening and clear. It’s absolutely essential when you have this change in life circumstances.” (Vulnerable Groups strand, participant with HIV)

“...if they had one hub to every benefit that you could get, which is probably not easy to get but, or at least like a signposting service or something where they’d say, ‘OK you’ve applied for this, did you know you’re eligible for this, this and this?’” (Survivors of Abuse strand, survivors of abuse participant)

A single point of contact and joined-up services

Some suggested having a single point of contact to avoid repeating their personal experiences, needs and health conditions. They also recommended a single point of contact as it would simplify the benefit system, help to have a clear communication and reduce waiting times. A few highlighted that having an allocated single case officer would avoid reliving their traumatic circumstances.

“But the people who are dealing with you [at DWP] just don’t seem to understand just how much going over it all again and again it’s like reliving the accident over and over again. [...] What they should do is simplify things; you should just have one person to deal with everything you can get.” (End of Life strand, participant living with a lifelong condition)

“A consistent point of contact would be good, because having to be on the phone for 6 and a half hours is time consuming. If you could leave a number for them to call you back that would be better too...” (End of Life strand, participant with terminal illness)

Some participants mentioned that benefit staff should provide guidance and signpost specific services that support the needs of specific groups. A few stated the need for various services to be more joined-up to help access and navigate social security services as a whole.

“I do think, and this is a broader thing, there should be just one place to call for help. There are hundreds of charities for ex-forces. I know there is meant to be a Veterans Gateway and then we have a Veterans Charter, but it does need to be more joined-up.” (Vulnerable Groups strand, veteran participant)

“There was no link between being an NHS patient and having a terminal disease and your being notified that you are entitled to benefits. So, that could have been better joined-up.” (End of Life strand, bereaved participant)

A small number mentioned their preferences for specialised benefit staff who provide them with benefit information and support for their specific circumstances and health conditions.

“So, in an ideal world they would have somebody there available to help you fill the thing out online or to make that phone call or to fill in the paper form, whatever it is. But that they’d know your individual circumstances before they do, and offering additional assistance for those that are fleeing domestic violence, because many times, most times they’re leaving with the clothes on their back.” (Survivors of Abuse strand, survivor of abuse participant)

“I think the main thing is having a team that really just deals with terminal illness and linked benefits and bereavement. I think that’s the main thing that I would add is important.” (End of Life strand, bereaved participant)

A few participants highlighted the need for a fast-tracked process for accessing benefits in the context of terminal illness and progressive health conditions. They mentioned that different services could communicate evidence and information to each other to simplify and speed up benefit processes.

“At the point of diagnosis, the patients’ particulars should be sent to the DWP with the diagnosis from the consultant and there should be a fast-tracking process so that the patient is not required to interact with the DWP or at least only to provide very few details. But, if the application was made on behalf of the patient automatically, and the relevant reward was given in a relevant timescale (i.e. within a matter of weeks) that would then minimise the stress to patients in completing these forms, minimise the stress to the patient in having to chase these things up and would leave the patient to deal and cope with what is really a life altering diagnosis.” (End of Life strand, participant with terminal illness)

Specialist and empathetic benefit staff

Many participants wanted the benefit staff to be fully trained and have regular updates on the system so they can provide comprehensive information about benefits, interaction across benefits and benefit changes.

“I think if everyone was actually trained on what the benefits currently are, because they change so often and I feel like no-one actually knows what the rules are.” (Survivors of Abuse strand, survivor of abuse participant)

Many also mentioned that staff should be trained to understand the specific circumstances of different groups such as survivors of abuse, terminal illness and bereavement. They reported that the benefit staff should be knowledgeable about health conditions, including those which are fluctuating and chronic. They also said that mental health conditions and their adverse effects needed to be better understood by benefit staff.

“I think there needs to be some staff training around trauma, because if someone comes in and is abusive towards you – obviously nobody should have to put up with that – but it might make it easier if staff were trained not only to deal with it and diffuse it, but the motivations behind it as well.” (Vulnerable Groups strand, homeless participant)

“Education. Yeah, education in mental health, education across the board. And people who know and have an understanding what it’s like to live with HIV, what it’s like to live with a mental health issue, rather than someone with no idea what it’s like to have these illnesses.” (Vulnerable Groups strand, participant with HIV)

Many noted the need for the benefit staff to listen to their circumstances and be caring and understanding of those. They mentioned that the benefit staff should treat the client with fairness, dignity and respect. Others mentioned that staff needs to be empathetic when communicating information and helping people with application processes.

“...you’re not judged based on what’s happened to you or whatever; and you’re treated fairly whether it’s a physical illness or a mental health illness or whatever the reasons are that you need help. [...] Coming to it with compassion rather than like, irritation that you exist almost.” (Survivors of Abuse strand, survivor of abuse participant)

A few mentioned that when the benefit staff communicate with compassion and without stereotyping clients, clients would respond more positively to the interaction too.

“That’s the first thing that needs to change, that pigeon-holing people. Marginalising people and saying ah they’re homeless, they’re an addict, They’re mentally ill. If there’s one place that shouldn’t be judging you for stuff like that it’ the benefit system.” (Vulnerable Groups strand, homeless participant)

“But really if Scotland are going to take over these [social security] services, I would hope it was done better so there is a bit of humanity behind it. PIP applications are about people who are vulnerable. [...] They should realise showing a bit more humanity would get more out of people. It’s more appropriate when dealing with vulnerable people....” (Vulnerable Groups strand, participant with HIV)

Waiting times and frequency of payments

Many participants proposed reducing waiting times between application and payment so clients could prevent financial hardship and minimise the length of financial uncertainty.

“I don’t know what would make the benefits system better. I suppose the speed of payment waiting for payments is hard. You are anxious already and then there is that uncertainty.” (Vulnerable Groups strand, prisoner participant)

A few said they prefer having monthly payments, others noted they preferred the payment fortnightly. A small number of participant also highlighted the potential issues with no having weekly payments for some clients. A small number of participants suggested that there should be options with the frequency of payments as it depends on individual circumstances.

“I think giving people payments more regularly would help, people need them every week or fortnight, not every month. Because day to day you are having to scrape an existence.” (Vulnerable Groups strand, prisoner participant)

“I prefer, personally to get it all at once. I think it would be easier if it was week by week but I personally, I would mess it if it was week to week. So, I do it in bulk and then for the month it’s like ‘Right, you’ve got this amount, here’s what you need’. If it was week by week, you’d think it’s not that much, it’s not a big deal, I’ve just got to wait another week and you might end up getting stupid things like buying a pizza or whatever. I’m fine with budgeting myself but maybe people who’ve got mental health issues might need help with budgeting.” (Vulnerable Groups strand, homeless participant)

A few suggested that the value of the benefit should increase to cover a minimum standard of living. They consider the current level of benefits to be too low.

“Nobody can live comfortably on the amount they get month to month through benefits at the moment. So, they need to think about the level of payment, as well as how often you get it.” (Vulnerable Groups strand, prisoner participant)

“The only other thing I would say is just that the amount of benefits is so low. £409 is a struggle even with cutting right back on everything but the essentials. I would say to the government to give people enough to live in dignity and get themselves back on their feet.” (Vulnerable Groups strand, homeless participant)

Simplification of processes by tracking applications, reducing waiting times and storing information

A few recommended the ability to track progress and updates of their applications. A few had positive experiences related to being given updates and reminders by email and texts. A small number of participants highlighted the need to have more updates so they can manage their finances better and feel less uncertainty. They also noted that tracking progress and having more frequent updates assures more transparency in the processes.

“...there really should be regular updates for people. [...] Maybe just a more transparent process really.” (Vulnerable Groups strand, homeless participant)

“Something to track progress, so you know where you are along the line. And people need to know to be able to budget, especially people with children.” (Vulnerable Groups strand, participant with HIV)

“I think, as well, having some more information about the status of things, like a ‘live monitoring’ of where things are at with different payments and benefits, that would be good. And something that tells you what you have to do still, in case you forget.” (End of Life strand, bereaved participant)

Some suggested shortening the waiting times between application and payment so clients could avoid financial difficulties. A few mentioned that if all the required information for an application is provided the long waiting times could be reduced.

“So yeah, if they could cut down on the wait times for people where they don’t have to go for emergency loans and things like that to make it through.” (Survivors of Abuse strand, survivors of abuse participant)

“Just, again, I think if you’ve given them all of the information they need [for a Funeral Assistance application] then it shouldn’t take four weeks for them to let you know if you’re gonna get it or not. Especially if they’ve got all the information they

need from the undertaker as well. Maybe just quicker and letting you know what's happening more [i.e. more regular updates]." (End of Life strand, bereaved participant)

A few participants thought it would be useful if personal information and evidence of the client could be stored centrally so they could avoid repeating their circumstances. It would also prevent requesting the same information or evidence from clients who are already in the benefit system.

"If Scottish Government are taking over it should help, if [personal information] it's not all scattered all over the place, that would help. And if records are central, it will avoid having to repeat yourself in different forms and to different people, and for the professionals I guess too." (Vulnerable Groups strand, participant with HIV)

A few mentioned that by storing information about the client, the benefit application processes would be simplified and improved. A small number of participants also noted that recording and storing information can trigger further specific support to the client.

"[recording personal information] so that would let everybody know that you've fled this domestic abusive relationship and could flag up other benefits you may qualify for other needs you may have. They could direct you 'cause some women may not go out into Women's Aid or to whatever Women's Aid and may not know where to go to get help and you know, they could signpost them to those places and give them information on those aspects as well." (Survivors of Abuse strand, survivor of abuse participant)

"I suppose people who do have disabilities...like everything that's sort of recorded or like they need extra support, I suppose that maybe is there for them already..." (Carers and Care Experienced strand, single parent participant)

Assessments and renewals

Some participants suggested that health assessments should be carried out by medical professionals as they have the expertise to understand physical and mental health conditions and their impact on daily living.

"Get doctors, real ones, not people who've done a few weeks of training. Just get actual verified real Scottish doctors so that when people are in Scotland, and they're seeing a doctor, there's no 'Oh I didnae understand them'. If they're looking to cut out fraud, make it a situation where there's no way for that to occur." (Vulnerable Groups strand, homeless participant)

Some mentioned that medical evidence provided by hospitals and GPs should be given more weight in health assessments and award decisions. A few suggested

that benefit staff should directly ask for the evidence from medical professionals to simplify the process.

“... maybe just getting permission from me to just contact my health care team directly and cut me out where they can go directly to get the information that they need.” (End of Life strand, participant living with a lifelong condition)

“I don’t understand why they can’t just see what your condition is, and what surgery you’ve had and what your diagnosis is and then base the awards on that, without asking all of the questions. It should be clear, I think, based on the medical information.” (End of Life strand, participant with terminal illness)

A few argued to reconsider the frequency of assessments for clients who have long-term conditions which are unlikely to change.

“...the other thing would be the award length, rather than two or three years. Because if you’ve got certain issues, there’s no cure. Like my headaches, they’re constant, they’re 24/7. So just make the awards a bit longer. Because when that comes up, that’s when your anxiety gets up.” (Vulnerable Groups strand, participant with HIV)

Flexibility in the system and wider support

A few participants highlighted that the benefit system needs to be designed with more flexibility so individual situations and sudden change of circumstances are taken into account. They mentioned that by focusing on individual circumstances as opposed to ‘universal’ situations, the benefit system would avoid some people falling in financial hardship.

“I think everyone’s circumstances have to be dealt with differently - there’s definitely not a ‘one size fits all’.” (End of Life strand, bereaved participant)

“...just not assuming everyone’s the same. Having one model for everyone to access UC, it’s ridiculous. It automatically puts people into debt ’cos it can be more than 5 or 6 weeks waiting for their first payment or because they get advance payments. [...] it needs more than one model, especially as it’s rolled out across the country.” (Vulnerable Groups strand, homeless participant)

“Treat people as individuals, with individual circumstances. There’s no such thing as universal conditions. People have different needs, abilities, circumstances.” (Vulnerable Groups strand, prisoner participant)

Some participants recommended the provision of specialised and wider support alongside the help with benefit payments. A few mentioned that the benefit system could provide an integrated plan for a client so they can be helped in a more comprehensive way.

“...I suppose it is more like a casework model but done properly. That you have a go-to person or team that would handle not just the money side of things, but also the health side if disability was the reason you were unemployed. To look at things like tenancy, housing. We’re calling it social security so the social aspect of it as well, like what kind of emotional support do people get. It’s not enough to give someone a couple of hundred pounds a month and leave it at that. [...] the system should be more integrated with social care in general. Show there’s a plan to stop them falling back into crime or addiction, get them out to NGOs that help people in the community.” (Vulnerable Groups strand, homeless participant)

“Skills and training are as important as money. The benefits system should not just think about money, it should be connected to things that help you get a leg up. There needs to be a connection between benefits and other things.” (Vulnerable Groups strand, prisoner participant)

A few suggested the provision of specific and tailored employment support. With that support they mentioned clients could develop skills and have access to training opportunities to be better prepared to get jobs. A small number of participants mentioned further services related with social care, crime and addiction prevention.

“If there was a system where you’re on benefits and then you’re able to sign up for training or work experience, if it could go like that I think half the people in the street would be off the street in three or four years.” (Vulnerable Groups strand, homeless participant)

“...there’s a lot more that could be done to help people, it’s not about giving people money. They need more in place to help kids now so they don’t get into drugs, get into problems with addiction, losing their homes.” (Vulnerable Groups strand, homeless participant)

“Benefits are only part of the picture too, there needs to be training and there needs to be opportunities.” (Vulnerable Groups strand, prisoner participant)

Third sector support

As mentioned earlier in the report, support from third sector organisations contributed to positive experiences with the benefit system. Many participants and respondents mentioned how they were helped by support workers from third sector organisations on different aspects such as providing clear information, completing applications correctly and attending assessments and appeals.

“Having someone to help you, like I’ve had a benefits worker from Macmillan, someone to support you and fight your corner. I think they need to know that can be important to a lot of people, to have that.” (End of Life strand, bereaved participant)

“...when I was applying for benefits the last time, I went into Streetworks in Edinburgh. They helped me with everything, they went on the computer. I just couldn’t have done it myself, I can’t work on a computer, I would have gotten enraged and frustrated with what they asked me. But they knew what they were doing and they were calm. It really helped.” (Vulnerable Groups strand, prisoner participant)

What's next

The chart below summarises the barriers that Seldom Heard Groups faced, the corresponding enablers and suggested improvements and sets out the actions Scottish Government and Social Security Scotland will undertake (or has already undertaken) to address these barriers.

Barriers	Enablers	Action
<p>The benefit system is complex and difficult to understand</p>	<p>Flexibility in the benefit system</p> <p>Key role of third sector organisations and support workers (for information, advice and support)</p>	<p>A general duty to promote the take-up of devolved benefits is enshrined in the Social Security (Scotland) Act 2018. The Scottish Government have, to date, published two benefit take-up strategies that set out approaches to maximising take-up, including addressing the barriers which prevent take-up, such as raising awareness of social security entitlements.</p> <p>Social Security Scotland will build on these findings by carrying out further research to identify and explore how best to communicate and raise awareness of benefits for seldom heard groups. The results of this research will be used to develop bespoke communication and engagement plans to support communication activity.</p> <p>The two benefit take-up strategies include engaging with stakeholders and partner organisations to address barriers to benefit take-up. The second Benefit Take-Up Strategy involves increased focus on engaging with organisations who represent seldom-heard groups. 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.</p> <p>The findings from this research are also used to inform stakeholder engagement</p>

		<p>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.</p>
<p>Difficulty finding information from official government channels</p> <p>Challenges with access to information and applications online</p>	<p>Consistent and comprehensive Information</p> <p>Various channels of communication and support</p> <p>Preferences for face-to-face support</p>	<p>Social Security Scotland has introduced inclusive communication approaches in all its work; pledging to provide clear and accessible information, and transparent explanation of the eligibility criteria for each benefit.</p> <p>There is a range of ways to apply for Social Security Scotland benefits, including online, telephone, paper-based or face-to-face. Further, applicants will be offered support when applying for Social Security Scotland benefits. This multi-channel approach will ensure that those who cannot or choose not to adopt digital methods will not become isolated.</p> <p>The findings from this research will feed into a joined-up approach to improve access to information and support, and the importance of providing a range of communication options.</p> <p>The findings on the preference for face-to-face support were fed into the development of the Local Delivery service in local communities across Scotland. This service is person-centred by providing a local presence to meet people's needs. There are currently 195 venues across the country where clients currently attend, along with home visits and remote appointments via telephone or video conferencing. Specially trained client support advisers provide pre-</p>

		<p>application advice and support to encourage people to take up the benefits and payments they are entitled to.</p> <p>The Scottish Government fund the Social Security Independent Advocacy Service which provides free support to disabled people when they are accessing and applying for Social Security Scotland assistance. The service enables clients to have their voice heard, express their views and feel understood ensuring clients are fully involved in processes and decisions which affect them.</p>
<p>Stigma from DWP and Jobcentre Plus staff</p>	<p>Specialised training of benefit staff</p> <p>Approachable and empathetic staff</p> <p>Benefit staff to be aware on mental health conditions and experiences of trauma</p>	<p>Social Security Scotland and the Scottish Government have taken a range of steps to ensure that dignity, fairness and respect are embedded in all aspects of the new system. Our Charter was co-designed with prospective clients 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.</p> <p>Decision Making Guidance for Social Security Scotland staff was developed with input from stakeholders. The guidance supports staff to appreciate the impact of living with mental health conditions, other fluctuating conditions, and learning disabilities, amongst others.</p>
<p>Complexity of the application forms and application processes (prescriptive,</p>	<p>Simplification of application processes</p>	<p>Social Security Scotland has introduced inclusive communication approaches in all its work including application processes, all systems and client/staff interactions.</p> <p>The design of forms and application processes are undertaken in</p>

<p>repetitive and long)</p> <p>Difficulties with getting supporting information</p>		<p>collaboration with people with lived experience of the benefit being devolved.</p> <p>Social Security Scotland has provided telephone and online services to advise clients on each aspect of the application processes.</p> <p>Social Security Scotland support individuals in understanding what supporting information would be helpful and how to get it. They can also gather supporting information on people’s behalf if they prefer. One piece of supporting information from a professional per application, where possible. This is to confirm the applicant's conditions, disability or needs. If this cannot be provided or gathered, for example because it doesn’t exist, the application can still be processed.</p> <p>Supporting information to help understand the impact the applicant’s conditions or disability have on their day-to-day life can be provided by a wide range of professionals or from people who know the applicant well, such as friends or family. Equal consideration is given to all types of supporting information.</p>
<p>Challenges with health assessments</p>	<p>Assessments carried out by medical professionals</p> <p>Reconsider frequency of assessments for people with health conditions unlikely to change</p> <p>Medical evidence to weigh heavier for health assessments</p>	<p>Adult Disability Payment consultations are carried out by qualified practitioners who have experience of working with people with different conditions and disabilities.</p> <p>Awards have no fixed duration and payment will continue during any review of a person's entitlement. Social Security Scotland have also introduced indefinite awards for some people whose condition is unlikely to change and are receiving the enhanced rate of both components of ADP or similar.</p>

	and award decisions	
Financial difficulties due to long waiting times of benefit payments	Reduce waiting times of application processes and payments	<p>At the moment, some award decisions are taking longer than it is desired. This is often because Social Security Scotland gather supporting information on behalf of clients. Collecting this information on behalf clients is a key difference between Social Security Scotland and the DWP.</p> <p>Social Security Scotland is planning to speed up processing times by working with groups and organisations who most often provide supporting information from clients. Through this, they are finding ways to simplify the process. For example, Social Security Scotland recently introduced an option for GPs to upload supporting information online.</p> <p>Universal Credit is reserved to the UK Government, and as such Scottish Ministers do not have the required powers to affect delays in processing applications and getting first payments out to applicants. However, The Scottish Government have written to the UK Government on several occasions specifically to ask them to scrap the 5-week wait for a first payment of Universal Credit, amongst other much needed improvements, including replacing advance payments with non-repayable grants.</p> <p>The Scottish Government will continue to call on the UK Government to act on these recommendations.</p>

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.

Annex A: Groups by Seldom Heard strand

The table below shows all the groups that participated in the Seldom Heard Voices research programme for both waves of fieldwork.

Table 10: Number of interview participants by seldom heard sub-group

Seldom Heard Strand	Group
Mobile Populations	Refugees
	Seasonal migrant workers
	Gypsy/Travellers
Vulnerable Groups	Homeless/those with experience of homelessness
	Prisoners
	People living with HIV or Hepatitis C infection
	Veterans
Carers and Care Experienced	Care experienced
	Single parents
	Young parents
	Kinship/foster carers and adoptive parents
End of Life	Bereaved people ⁸
	Adults living with a terminal illness
	Carers of individual with a terminal illness
	Adults living with a lifelong condition
Survivors of Abuse	Survivors of domestic abuse

⁸ Bereaved people included people who lost a child, a parent, or a partner.

Annex B: Recruitment and engagement insights

This section focuses on presenting key insights on recruitment and engagement with seldom heard groups. These insights were provided by the companies which carried out the research fieldwork for the two waves of fieldwork.

Barriers Challenges to doing research with Seldom Heard groups

Support organisations contacted for recruitment were receptive of the research and were usually happy to act as gatekeepers. However, barriers were presented when engaging with some of them which impacted on the recruitment and produced delays in carrying out the fieldwork. These were:

- Organisations sometimes were too optimistic about the number of participants they thought would participate in the research.
- Organisations often experience difficulties identifying willing participants.
- Some advocacy and national organisations who provide strategic or specialised support to certain seldom heard groups do not have direct access or cannot contact directly research participants.
- On the initial contact requesting support for recruitment, some organisations do not know where to direct the research inquiry for action.
- Lack of resourcing and busy services among support organisations impact on their ability to assist the research due to competing demands.
- Engaging with local authority services for recruiting potential participants could take significantly more effort and time as they do not only need to identify relevant contacts but also:
 - Research teams also need to complete forms to request permission for access and waiting for those to be approved.
 - Following those processes do not guarantee a high number of participants either.
- Lack of dedicated advocacy and support organisations for some seldom heard groups have an adverse impact on the research engagement of these hard-to-reach groups.

There were challenges found by the companies who carried out fieldwork concerning some participants or with specific seldom heard groups:

- Some seldom heard groups – such as young parents, care experienced people and Gypsy/Travellers – may have particular concerns about engaging with research.
- Some participants felt discouraged to engage as a result of requests to read information sheets and complete consent and demographic forms before the interviews. This was particular the case for participants with literacy issues.
- Some participants have more privacy concerns and lack of trust than others.
- Some participants have potential barriers for their engagement including: lack of English proficiency, lack of phones, technology illiteracy, prison regime.

- Plans with interviews were frequently cancelled by some participants.

Barriers specific to the Coronavirus (COVID-19) pandemic

The measures imposed to manage the COVID-19 pandemic significantly impacted on the recruitment and engagement across the seldom heard groups. The impact of the pandemic resulted not only on the reduction of the number of research participants for the Seldom Heard Programme; but also on the termination of one contract with the organisation leading the research with women who experienced domestic abuse.

Challenges during the COVID- 19 pandemic that impacted on recruitment and engagement with support organisations were:

- Support organisations experienced staff shortages and absences.
- Organisations were prioritising essential support to their service users.
- Staff from organisations were working remotely and ceased most of their face-to-face contact with service users. This hindered effective communication with key contacts that could support the research.

Enablers for engagement with seldom heard groups

Contractors provided suggestions to engage with seldom heard groups. Key suggestions for the recruitment phase are the following:

- Consider that the recruitment and engagement processes with hard-to-reach groups are very time consuming.
 - Some organisations which helped with recruitment needed to discuss their endorsement of the research at the management/senior team level.
 - The process of identifying potential participants is lengthy.
 - Planning a longer lead time for recruitment is necessary.
- Use previous contacts from support organisations for initial engagement with gatekeepers.
- Use snowball strategies to recruit participants.
- Allow participants to share information of the research with their peers.
- Keep an active and continuous engagement with support organisations to establish contact and build continuous trust with gatekeepers.
 - In many cases, this could be better established with in person communication.
 - Communicate the purpose of the research clearly.
- Be creative when contacting potential organisations to recruit participants of specific seldom heard groups which do not have dedicated or advocacy support organisations. Some potential organisations can be:
 - Housing and financial organisations.

- Organisations which provide non-financial support to seldom heard groups.
- Use media engagement tools and produce digital equivalents of information sheets, posters or flyers.
- Use plain English and reduce the length of information sheets, posters and flyers for initial recruitment purposes.
- Provide more detailed documentation once participants show interest to take part.
- Consider interviewing staff from support organisations.
 - Many of them have significant amount of direct experience of interacting with social security agencies themselves on behalf of their service users.
 - The views of support workers are likely to highlight issues they encounter among large number of people they work with, which may be an indication of the prevalence of different barriers and enablers to accessing benefits on the wider scale.
- Pay travel expenses and provide financial incentives such as shopping or gift vouchers. These are key factors to engage with seldom heard groups.

Contractors also highlighted the need to be flexible about setting up the interviews and focus groups.⁹ They provided the following suggestions:

- Be respectful of the specific conditions and requirements of some Seldom Heard groups.
 - Some would not want the interview to be recorded.
 - Some would feel more comfortable to discuss their experiences with peers they already know.
 - Others may prefer to take part in the research in individual interviews instead of a focus group.
- Consider the specific needs of certain participants.
 - Female researchers may be required to interview female participants for certain groups.
 - Offer translation support when needed by participant.
 - Rearrange interviews at short notice due to participant's illnesses.
 - Consider prison's regime and their timetables.
- Minimise the requirements to complete documentation for participants, including the process to gather consent and demographic information. Provide the option to gather this information verbally.
- Consider setting up interviews and focus groups alongside pre-existing events with participants that are comfortable discussing the topics in front of their peers.
- The quality of facilitation is very important in group settings.
- Book suitable venues that fit the particular circumstances of participants (e.g. participants that will attend with their babies).

⁹ During the first wave of fieldwork with participants from the Carers and Care Experienced strand, several focus groups were carried out by Blake Stevenson - the company commissioned for the fieldwork.

- Be flexible about when the focus groups and interviews can take place.
 - For some participants it is more suitable to speak in the evenings or weekends.
 - Some participants may want to be interviewed at home.
- Offer various channels of communications to carry out the interviews or focus groups: online, by telephone, in person. Each participant would have their preference and individual needs.
- Be prepared for cancellations and missed appointments.

Annex C: Number of interview participants by seldom heard groups

Challenges in recruitment resulted on a varied number of participants in wave 2. The table below shows a breakdown of the number of interview participants by Seldom Heard group.¹⁰

Table 11: Number of interview participants by seldom heard sub-group

Seldom Heard Strand	Group	Total
Vulnerable groups	Homeless/those with experience of homelessness	11
	Prisoners	8
	Living with HIV	4
	Veterans	1
Carers and Care experienced	Care experienced	2
	Single parents	13
	Young parents	2
	Kinship/foster carers and adoptive parents	7
End of life	Bereaved people ¹¹	9
	Adults living with a terminal illness	5
	Adults living with a lifelong condition	2
Survivors of abuse	Survivors of domestic abuse	3

¹⁰ A total of 8 interview participants from the Gypsy/Traveller community participated in wave 2 of the Mobile Population strand. They are excluded in the table as the findings have already been published.

¹¹ Four interview participants were bereaved following a terminal illness of their loved ones.

Annex D: About interview participants and survey respondents

Where possible, information provided by participants and respondents was collated to present demographic data. The following tables are included to give context to the findings of this report. The tables show proportions based on available information and the total number is given as (n) in the table title.

Table 12: Location (n= 80)

Local council area	% of respondents/participants*
Glasgow City	26
Fife Council	14
City of Edinburgh	10
North Lanarkshire	8
Aberdeenshire	6
Dundee	5
The Highland	5
West Lothian Council	4
Inverclyde	3
Midlothian	3
Scottish Borders	3
Angus	1
Argyll and Bute	1
Borders	1
Dumfries and Galloway	1
Falkirk	1
Forfar	1
Greenock	1
Kirkcaldy	1
Lanarkshire	1

Moray	1
Slough Borough	1
South Lanarkshire	1

* Figures may not add to 100 per cent due to rounding

Table 13: Age (n= 89)

% of respondents/participants*	
17-19	8
20-24	2
25-34	28
35-44	26
45-54	25
55-64	7
65 or over	5

* Figures may not add to 100 per cent due to rounding

Table 14: Gender (n= 91)

% of respondents/participants*	
Female	67
Male	32
Prefer not to say	1

* Figures may not add to 100 per cent due to rounding

Table 15: Ethnicity (n= 91)

	% of respondents/participants*
White	74
Ethnic minority	6
Prefer not to say/no answer	21

* Figures may not add to 100 per cent due to rounding

Table 16: Long-standing illness, disability or infirmity (n= 79)

	% of respondents/participants*
Yes	56
No	43
Prefer not to say/no answer	1

* Figures may not add to 100 per cent due to rounding

Table 17: Caring responsibilities (n= 51)

	% of respondents/participants*
Yes ¹²	53
No	45
Prefer not to say	2

* Figures may not add to 100 per cent due to rounding

¹² Caring for an adult or adults with long-term health physical/mental ill-health/a disability, a child or children with long-term physical/mental ill-health/a disability or for an adult or adults who needs support due to old age.

Annex E: Main challenges concerning specific sub-groups

The reports of the first wave of the Seldom Heard Voices research programme showed the main challenges and enablers for each specific group of the [mobile populations strand](#), [carers and care experiences strand](#) and [vulnerable groups](#).¹³ Similar findings have been found for those specific groups in the second wave. However, frequent barriers and enablers of new specific groups interviewed in wave two were identified and they are presented below.

Prisoners

Re-offending and financial hardship

Many prisoners have experiences of drug addiction and destitution.¹⁴ Most prisoners mentioned that a key reason for re-offending was not having any financial support just after being released and people could not cope with the changes of being out of prison immediately. Many said that the waiting period to access benefit payments and services after being released was the cause for committing a crime again.

“I’m concerned for the people in here because often they get out of prison and they don’t have help to know what to do. And they might be able to claim for something to help them, but they are left waiting 6-13 weeks to get a payment. It’s like a revolving door in here. I’m in four and a half years so I’m seeing who comes and goes. Many have good intentions when they leave, but then it hasn’t worked out. They got to a point where they couldn’t cover costs and they turn to things like shoplifting and fraud. It’s triggered when there is a delay or a gap in something they should get through their benefits.” (Vulnerable Groups strand, prisoner participant)

“...those first few weeks are frantic, you are running about the place, you’re trying to get a roof over your head, you’re going to charities to help you, you’re dashing about. I couldn’t cope with that last time. A couple of weeks of that and I gave up. Much easier to get money through theft than wait for the benefits to kick in. I think about 90% of the prison population would agree with that unfortunately.” (Vulnerable groups strand, prisoner participant)

¹³ The findings of the [report of the End of Life strand](#) of wave 1 focused on the main challenges and enablers of 11 participants who were living with terminal illnesses or were carers of people who have terminal illnesses. Only one participant was a bereaved person who lost her husband due to terminal illness. As a result, we are including findings of bereaved people in this section as it is a new specific sub-group interviewed as part of the End of Life strand for wave 2.

¹⁴ Some participants who had experiences of homelessness in wave 2 had also experiences of addiction and being in prison at some point.

Some also provided further reasons for re-offending: experiencing benefit sanctions, not being able to access paid employment due to their criminal record and having poor literacy skills to complete benefit applications without support.

“I’m sat here in prison and I know quite a few people who can’t read or write. And they’ll just be let out and expected to be able to claim for benefits and fill in forms. They won’t be able to without help. For them committing crimes is the easy option, they don’t need to read or write to do that.” (Vulnerable Groups strand, prisoner participant)

“Being sanctioned meant I didn’t get any money for three months. And then I didn’t have any family and friends to turn to. So, I got back involved with crime, just to have money for food initially. But then you’re around drugs and I’ve had an addiction, so it sucks you back in. Especially if you don’t have a support network.” (Vulnerable Groups strand, prisoner participant)

Some mentioned that the wider context of people not being able to cover their basic needs as a reason to turn into petty crime such as shoplifting. A few also noted that some prisoners prefer to stay in custody as they feel their basic needs such as housing and food are covered.

“...for many of the guys in here it’s simply down to poverty. I see people come back in and they say to me that they are better off in here. It’s sad to think that for them to get a meal and a warm bed they have to come back to prison.” (Vulnerable Groups strand, prisoner participant)

“Since I have been working age the most comfortable I’ve felt has been when I’m in prison. And I’m sorry to say that. It’s like the better of two evils. I was always having to borrow money and getting into a vicious circle. In here I don’t need to worry about how I can live week to week...” (Vulnerable Groups strand, prisoner participant)

Lack of awareness and communication channels

Many prisoners were not sure about which benefits they will be eligible once they are released. A few also felt anxious and stressed for the waiting period to get the benefit payment as they felt they will not have any other financial support after their release.

“But now I’m coming out I’m worried about money again. Because I don’t know what benefits I’ll get, how long for and then if there is a problem I could fall back into the crime and the drugs. I don’t want to but it’s a risk. It would be like history repeating itself.” (Vulnerable Groups strand, prisoner participant)

One barrier noted by a few was the lack of a mobile phone or a personal computer to be able to claim benefits or follow up benefit applications and processes. They also noted the potential issue of not having a permanent address required to start and follow up those processes.

“For anyone to contact me about a benefit claim when I get out that’s tricky. I don’t have a mobile or a computer. I don’t know what my address will be when I get out, I don’t know if they’ll be a landline where I’m staying. So how do you contact someone without an email, number or address?” (Vulnerable Groups strand, prisoner participant)

Need for support prior and after release

A few recommended prisoners were provided support with benefit information and with application processes approaching their release. Many prisoners said if they could apply for benefits when being in custody, they could access benefit payments just following their release and hence avoid the waiting period and falling on financial hardship. A few also noted that getting benefit payments following their release could reduce re-offending.

“You need to be able to apply for benefits whilst you are in prison to get the ball rolling [...] you should definitely be able to apply for benefits whilst you are in prison. That’s really important and we are saying that on behalf of everyone in here. Everyone would like to do that to avoid that gap when they get out.” (Vulnerable Groups strand, prisoner participant)

“It’s a worry sorting everything out when you come out. Last time I came out it was frantic with all the things to do. And if you can do something before you get out to set you up for when you get out that is a great help [...] I’m worried about when I get out and not having benefits in place right away. I’m worried about applying and waiting for benefits. When you get out you have to sort housing, a bank account, bank cards, getting a phone so people know how to get in touch with you. You’re thinking about food. It’s a lot to suddenly do without support [...] the thing about being able to do things whilst you are still in prison is that you could get things set up easily. If there were staff in the prison with the means and the role to help you with things like applying for your benefits online [...] a lot of people are reoffending quickly because they get out and can’t cope right away. If you could have a safety net and something in place those first few weeks it would reduce re-offending.” (Vulnerable Groups strand, prisoner participant)

Some prisoners mentioned their need to access wider support once they are released. A few noted that this wider support needs to be linked with the social security system. They said that services they need included rehabilitation for addictions and services on training and employability.

“I’m on methadone and I need to go into rehab because I need a support system. It’s not just money, it’s a support system too. You need both really. [...] skills and training are as important as money. The benefits system should not just think about money, it should be connected to things that help you get a leg up. There needs to be a connection between benefits and other things...when you sign up for Universal Credit you also can say if you are willing to sign up to employment support groups. But then those aren’t funded well. It’s just a tick box exercise at the moment. More needs to go into that wider support.” (Vulnerable Groups strand, prisoner participant)

“Social security should be a help to transition you. It is to carry you when you are in need. But it also needs help for training, to get into work. If there was more money put into those things fewer people would be on benefits, or they would be on them for less time.” (Vulnerable Groups strand, prisoner participant)

Survivors of abuse

Distrust of the benefit system

The survivors of abuse interviewed reported that going through the application and assessment processes made them feel anxious or in fear. They felt benefit staff did not believe or did not want to listen their experiences. They also felt they did not have any control of benefit processes and their outcomes. A couple of participants perceived benefit processes like a continuation of domestic abuse.

“...it was like the financial abuse part of it and I was like this is a way of them, in my experience, keeping that control there and that being continued. And it’s like I’d got out of the horrendous situation and now I’m out of it, I’m still being dragged through it. So, for me it was like, well it still is continuing abuse in my head and I can’t get out, I can’t navigate that away. I understand and I think that’s a fair analysis of when you’re in an abusive relationship or come out of one; your priorities are all over the place and it’s just one thing can kind of set you off. And for me that definitely was my experience of the current system. They didn’t understand. There was very little empathy [...] I think it’s like continued control feeling. You can’t get away from it because not only have you come out of that relationship, you’ve now got a government body continuing control.” (Survivors of Abuse strand, survivor of abuse participant)

“I don’t know how to put it but, like when I got for example my PIP letter back, which I got first before Universal Credit, they rejected me and they gave me a list of reasons why and half of the things I hadn’t even said and I just felt a bit like oh [sigh]. And then because I’d experienced domestic abuse and stuff and like all the gaslighting, I started doubting myself. And then that causes this whole thing in your head and so, yeah, it just [sigh] it was a bit of an ordeal...” (Survivors of Abuse strand, survivor of abuse participant)

Participants reported that the benefit staff asked specific questions to stop people making successful applications. A couple of participants mentioned that they avoided reporting any changes in circumstances or challenging the outcome of an application or medical assessment out of fear that their benefit payments may be reduced or stopped.

“In her opinion I could walk farther than what I told her. I could walk, basically and I’m like, ‘Well where’s your medical evidence for that, ‘cause I’ve got loads here that says I can’t, and that I’m in constant pain. Even walking under 50 metres is painful for me so I don’t know where you’re getting this.’ But sometimes they [advisors from support organisations] say it’s just not worth it. You can challenge it and lose everything, so I can’t see that I would but, it’s just stressful to go through it all.”
(Survivors of Abuse strand, survivor of abuse participant)

“...it definitely feels like it’s set up to catch you out [...] And one of the things she asked me...like had I walked anywhere or had I seen any of [local area]. It was a very small sort of like conversation and I’d literally been out once and I said, ‘Oh yeah, I finally saw the sea the other day.’ And she made it into such a big deal; so I can’t possibly be depressed and stuff like that. And I just thought that’s so cheeky to like extend that bit of the conversation, but you can’t go into detail on the stuff I’m actually giving you information about. So, it definitely feels like it’s set up to fail.”
(Survivors of Abuse strand, survivor of abuse participant)

Lack of awareness of domestic abuse

All participants noted that applications were restrictive, complex and did not allow them to convey their circumstances. They felt their experiences of domestic abuse and their psychological, physical and financial consequences were not recognised when they were explaining them to the benefit staff.

“...and no flexibility, that was definitely one of my things. I just felt there was no deviation or understanding of a situation it was just one size fits all and that, that’s not the way that we should be going forward with [...] the process that I went through was, was not very helpful at all. It was as I said. There was no understanding, it was just black and white it was either yes or no, there’s no in between. I felt like they were judging me when I would say things and then I would be penalised for it.” (Survivors of Abuse strand, survivor of abuse participant)

One participant mentioned that when reporting a change in circumstances, benefit staff asked her to contact the abuser or the abuser’s family. She noted this experience as staff having a lack of understanding on domestic abuse.

“...it just shows that there’s just not much of an understanding there when what they’re asking you to do is not something that’s easy for people of domestic abuse situations. [...] I don’t have contact with them. I don’t want to have contact with them, but they were making me go into a situation where I was gonna have to potentially do that and pull them back into a life that I’m trying to get away from.

So, yeah it was horrendous, horrendous, when I think about it now... [...] you're asking me to speak to my ex partner [inaudible 0.41.05] that in a situation that we're in right now and you know, there's police involvement and I can't do that."
(Survivors of Abuse strand, survivor of abuse participant)

Essential need for support

All participants noted that when fleeing domestic abuse, women need support with getting information and application processes as the abuse had a negative impact on their mental health. They mentioned positive experiences in which workers from support organisations helped them with applications because they understood what they were going through.

"I couldn't sit and fill out a form anymore which was frustrating and embarrassing and she [support worker] was, she was just wonderful. She helped fill out all the forms, she didn't make me feel, she made me feel comfortable and like she understood and she was compassionate and took the time with you, not just trying to rush you through your appointment." (Survivors of Abuse strand, survivor of abuse participant)

A couple of participants also highlighted that information and evidence provided by support or advocacy workers on their behalf were disregarded during assessments. They suggested that evidence given by these workers should be considered. They thought support workers sometimes are in a better position to speak on their behalf about their experiences of domestic abuse.

"...when we went to the actual face to face interview, anything I said would be the only stuff that they'd write down. So she [support worker] wasn't allowed to put anything across for my benefit and I, at the time my mind was so frazzled [...] anything that she said couldn't get taken into the statement, basically [...] the reason why I brought this up in the first place was, she was allowed to go to my doctor and get information, she was allowed to go, so she gathered all the evidence for me 'cause I couldn't, I just couldn't do it. She went to the council who were dealing with financial problems for me and she gathered information from them. She was like a little magpie collecting all the information for me. [...] And so, if she's allowed to go and get, gather information from my doctor, surely, she can speak on my behalf? It was just a weird thing to happen." (Survivors of Abuse strand, survivor of abuse participant)

All participants suggested the provision of training in how to support women experiencing domestic abuse for benefit staff and support workers. They highlighted the need to increase domestic abuse awareness, in particular among benefit staff who they felt did not recognise their experiences.

“...I think definitely understanding that these women aren’t lazy they’re traumatised, you know? And understanding the whole dynamics of it [...] I definitely think a lot of training needs to be done in the benefits system on domestic abuse.” (Survivors of Abuse strand, survivor of abuse participant)

“How can we pass a new domestic abuse act and not update the relevant support networks that are there for us?” It’s very like, not necessarily backwards but I think it’s like you can’t fix one thing without fixing all the other pieces [...] like it is legislation [Domestic Abuse Scotland Act] so we should recognise, they should recognise that in a policy somewhere [...] it helps to build confidence for us you know, to know that we can go competently to a new social security system. That we’re gonna be there to be supported and protected the way we should be.” (Survivors of Abuse strand, survivor of abuse participant)

Participants suggested if information about their domestic abuse could be recorded within the social security system so whenever they need to communicate with staff, they avoid repeating their experience to different advisors or assessors. They also mentioned that recording this information regarding experiencing domestic abuse could also lead to signpost clients who are fleeing domestic abuse to other eligible benefits, services and support organisations.

“Not, you know, needing to tell her story a million times and having different reactions. It should just be, I’m a victim of domestic abuse or I’m a survivor of domestic abuse. [...] We shouldn’t have to, you know, repeat it unless we need to, you know, for whatever reason. It should just be accepted [...] It’s having that ability to express a bit of flexibility and express a bit of, “This is my situation, please have a little bit of understanding there.” (Survivors of Abuse strand, survivor of abuse participant)

Bereaved people

‘Tell us once’ service

Most participants used the [‘tell us once’](#) service to notify the death of their relatives to government organisations like DWP and Social Security Scotland. They were aware of that service through the registrar office, support organisations or their informal networks.

“When you register their death, there’s this ‘Tell Us Once’, and they just cancelled the housing and the benefits and things.” (End of Life strand, bereaved participant)

Many mentioned that by using this service, the benefits claimed by their relatives were stopped and that was confirmed when they received a formal letter notifying the change. Some also noted that the ‘tell us once’ service provided them advice on what benefits they could claim in their current circumstances.

“... it was the Registrar who offered that they could do that thing where they tell people once, and then they let everyone know. So, they did do that. They let DWP know and then I got a letter through afterwards that they had been notified and that the benefits would stop.” (End of Life strand, bereaved participant)

“It was actually when I went to register the death that they gave me like, I think it was a code. Because my husband was on sickness benefit at the time, and he’d only just really been awarded that, but it was really just to notify them to cancel his claim and from that information I was then obviously told what benefits I would be able to claim as a bereaved single parent.” (End of Life strand, bereaved participant)

Most participants had positive views on that service as they perceived it as a simplified and efficient system. They mentioned that because of using it, they were able to focus on other tasks around the death of their loved one.

“I think it was easy that it was just one call that I had to make, and I didn’t have to call different departments to speak to people, so that works really well. When you have a bereavement or a death, you’re already needing to contact so many different people - funeral directors, family, and so it just made that whole part of my life easier.” (End of Life strand, bereaved participant)

Interacting with support organisations and benefit staff

Many participants highlighted the help provided by support organisations for various tasks they had to carry out after the death of their loved ones. They gave them information about arranging the funeral, its costs and/or information about benefit entitlement. In some cases, they also gave them support by directly contacting government organisations and by completing forms.

“...Funeral Link [Dundee], they put me in touch with both DWP and Social Security Scotland and they helped me figure out whether or not I was eligible and whether or not I could claim and talked me through the funding that was available.” (End of Life strand, bereaved participant)

Some participants stressed the relevance of having support organisations who were understanding of their bereavement experiences. A few noted their grief impacted their ability to carry out benefit processes and new arrangements so having the support of these organisations was essential for them.

“...I’m having days where I’m grieving, I’m trying to cope with the loss and my emotions and my health has gone downhill so badly since I lost [name] that even just answering the phone some days, I just can’t do it. [...] My Macmillan workers have been great. Just, even when I didn’t want to phone up about money, [name of support worker] just had the most gentle persuasion, and she encouraged me with what I needed to do.” (End of Life strand, bereaved participant)

“I just think it was really, really helpful to have Funeral Link. [...] she was amazing at offering support and care and letting me ask questions and asking if I knew where to go for support. [...] I don't think I would have managed without them [Funeral Link] and got through it all.” (End of Life strand, bereaved participant)

Some had to communicate directly with benefit staff from DWP and Social Security Scotland regarding the changes of their benefits. Overall, they highlighted that communication as positive.

“Getting information from the social security helpline quite early on certainly did help relieve that side of things - the stress and worry about money [...] And, I would say that the phone call I had early on [after the death], that was really helpful because I didn't think that I would be entitled to anything. [...] They were very sympathetic and very understanding of what I was going through. They were actually really, really helpful and I got the impression that they were quite well trained[...] It was just one point of call that I had to make and just speaking to one person who was proactively giving me advice as to what benefits I could get or was entitled to claim. (End of Life strand, bereaved participant)

“The contact I then had with Social Security Scotland was then quite a quick process and that was really helpful. (End of Life strand, bereaved participant)

“What I would say is that they were very good, the social security, they did call me and make sure everything was alright and that all the money had been gotten and the funeral director paid and things. So, that was good - after the funeral.” (End of Life strand, bereaved participant)

However, a couple of participants also noted the need for having staff who know more about bereavement and grieving. A couple also mentioned that having a face-to-face option to interact with benefit staff could help to get a more personal approach to people who are bereaved.

“Ideally, without the pandemic in the mix, if there was just a number and just a team that knew about terminal illness and death and afterwards, what people should do. That would probably be good for most people.” (End of Life strand, bereaved participant)

“I think it probably would be better if you could see someone face-to-face because when you're on the phone, it just feels rushed somehow. It's like someone has just, how can I put this, it's very impersonal and you feel like you're just someone else that they [person on the phone] has got to deal with before they go on their break.” (End of Life strand, bereaved participant)

A couple of participants suggested the need for a single point of contact in benefits agencies which could help to reduce the waiting period and to avoid repeating their circumstances again and again. This single point of contact could also help to signpost other services.

“The big thing is that it’s time consuming, and it’s frustrating, being passed from place to place. Even just having one person you can keep calling back instead of different departments and things.” (End of Life strand, bereaved participant)

“I think as well, maybe if DWP or whoever you speak to on the phone if they could just point you in the direction of people like Cruse, or people like that who can maybe help with bereavement, that might be helpful too. I think that would make it a very human response as well.” (End of Life strand, bereaved participant)

“I think the main thing is having a team that really just deals with terminal illness and linked benefits and bereavement. I think that’s the main thing that I would add is important.” (End of Life strand, bereaved participant)

Benefit changes after the death of a loved one

Some participants were eligible for Funeral Support Payment. A few highlighted positive experiences with the process and described it as simple and easy to access. However, a few participants also mentioned their financial worries of not knowing the outcome of their applications due to the waiting times.

“I had one follow-up call, which was fine. But then I had quite a long wait to find out whether or not I would get it, maybe like a month. I know that maybe doesn’t sound like a long time, but when you’re talking to a funeral director, and you’ve maybe not paid them, it’s quite stressful. [...]if they decide that they’re not gonna give you any help, it doesn’t leave you much time to try and find the money somewhere else.” (End of Life strand, bereaved participant)

A few participants highlighted some benefit issues related with overpayments and passported benefits. One participant said that there was an overpayment issue in the account of her late relative which has remained unresolved. Other participant mentioned that as a child related benefit was linked to her late husband, that payment was stopped and that resulted on her not being eligible to a passported benefit that she and her advocate worker knew she was entitled to.

“There is a big outstanding issue for me with DWP regarding my mum’s death and benefits. And that all started when we discovered that my mum actually had quite a lot of money - it was quite a surprise really. [...]The solicitor had said that they notified the DWP, but there’s maybe payments that have been made that shouldn’t have been made and we would need to pay them back. But, that’s over 9 months now and we’ve heard nothing. And seemingly, it can be over quite a few years before they do sort things like that. And it can be quite unsettling [...] The solicitor

has been in contact with DWP and she did say that there might be a delay because there is such a backlog. And, I did ask, “Normally, how long would it take?” and she said that it is just different for everyone - for some it could be months and for some it could be years.” (End of Life strand, bereaved participant)

“Well, obviously these grants are dependent on what benefits you’re on, and we were on child tax credits and so obviously, when my husband died, it seemed that they just went with him. So, I would just basically be left with nothing but I didn’t realise when I applied [for the child grant]. So, I got a phone call to say that I wasn’t eligible for the grant because my child tax credits had finished and that’s how I came to learn really. I was really shocked.” [...] “So, I spoke to a benefits worker at Macmillan and she explained “Well, we’ll try and do a redetermination thing.” (End of Life strand, bereaved participant)

Annex F: List of abbreviations

List of commonly used abbreviations in this report

CB: Child Benefit

ESA: Employment and Support Allowance

DLA: Disability Living Allowance

DWP: Department for Work and Pensions

GP: General Practitioner

HB: Housing Benefit

JCP: Jobcentre Plus

JSA: Job Seekers Allowance

PIP: Personal Independence Payment

UC: Universal Credit

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 for further information.
- cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



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