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# **SOCIAL SECURITY EXPERIENCE PANELS - SELDOM HEARD PROGRAMME OF RESEARCH: VULNERABLE GROUPS**



**Equality, Poverty and Social Security**



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# Summary

## Introduction

In 2017 Social Security Scotland set up Experience Panels to help in the design, delivery, oversight and review of Scotland's new social security system. These panels are made up of over 2,400 people who have experience of at least one of the benefits that will be, or have been, devolved to Scotland. We found some groups were less likely to be in the Experience Panels and extended the research programme to bring in some "seldom heard voices". This research was designed to ensure their voices are included in the design of social security services.

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

This is the report for the first wave of the Vulnerable Groups strand. The group is divided into the following subgroups: 'Military Veterans', 'Homeless', and 'HIV or Hepatitis C'.

## Background

Participants in these vulnerable groups can live with multiple debilitating conditions, ranging from mental and physical illnesses, to drug and alcohol dependency. In addition, trauma - whether stemming from sexual or domestic abuse, war-time experiences, or the onset of physical injury or infection - was a common lived experience among many research participant interviews.

Some participants were deeply embedded in support networks, including third sector organisations, family and friends and health and social workers. Others lived in isolation and felt disconnected from support services and social networks.

This report highlights key barriers to accessing the benefit system, as well as enablers to benefit uptake experienced among the Vulnerable strand participants, as identified through analysis of qualitative interviews.

## Summary Findings

### Barriers

Research findings suggest that participants in this group often struggled to find information on benefits and which benefits that they are eligible for. For those who have experienced the benefits system over many years, the system was described as having become increasingly complex, inflexible and inaccessible. Because of such complexity, many participants described feeling 'unsure' as to whether they filled in application forms the 'right way'. This increased participants' reliance on third sector organisations to help fill in forms.

The rigidity in application form and health assessment processes also led participants to voice concern, and indeed frustration, at not being able to express or have recorded the nuances of their individual life experiences. Notably, this occurred for individuals who lived with complex and fluctuating health issues.

For some, a perceived lack of face-to-face 'human contact' with benefits agency staff was felt to perpetuate these difficulties, as they found it difficult to navigate the online benefits system. For others, it was felt that benefit agencies were purposefully trying to 'catch you out' in application forms and assessments to discourage people from applying. This left many participants feeling stigmatised and discriminated against.

For those who had experienced trauma (often associated with Post Traumatic Stress Disorder (PTSD) or domestic/sexual abuse), benefit assessment staff were unanimously found to be poorly trained to deal with these issues. This was in relation to the Personal Independence Payment (PIP) assessment. Participants were strongly critical of the impact PIP assessments had on their mental health. Participants variously reported feeling "humiliated" and "disbelieved" by assessors, while GP/psychiatric evidence was not taken into account.

Some participants felt official reports, based on health assessments, were inaccurate and one-sided. Participants were critical of a social security system that

does not allow for assessment reports to be revised or co-authored by the research participant themselves or an independent witness without going through a stressful appeals process. For those who went through the PIP appeals process, several expressed their inability or unwillingness to go through the stress of an appeal without support from third sector organisations.

### Enablers

When asked about the future of the benefits system, participants identified key enablers they perceived would help them access the benefits system.

The majority of participants called for application forms to be made simpler, for the use of more straight forward and clearer language (no-jargon), so that they were easier to fill in. Some also wanted Department of Work and Pensions (DWP) assessors and helpline staff to be better trained to treat people with vulnerabilities, in particular those with mental health issues.

Many participants, when told of Social Security Scotland introducing local delivery services, were in support of this service. Participants variously described the need for service delivery staff to be caring, professionally trained and good listeners, who would treat them as 'human beings'.

# Introduction

The Social Security Experience Panels were established by researchers in the Scottish Government in 2017. Scottish Government researchers work with members to bring the voices of those with lived experience into the design of the new social security system in Scotland, as run by Social Security Scotland. There are groups of people with lived experience that are less likely to be represented on the panels, so the “Seldom Heard Voices” 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 groups identified as ‘Seldom Heard’ in this research programme. They are Mobile Populations, Vulnerable Groups, End of Life; and Carers and Care Experienced. For each group two waves of fieldwork are being undertaken.

This is the report for the first wave of the Vulnerable Groups strand. The fieldwork was undertaken by Mark Diffley Consultancy and Research (now Diffley Partnership) between 2019 and 2020. The analysis was carried out by Scottish Government researchers.

A total of 20 participants were interviewed from the following subgroups: ‘Military Veterans’ (7 participants)<sup>1</sup>, people currently or having previously been ‘Homeless’ (7 participants), and people living with HIV or Hepatitis C infection (6 participants).

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

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<sup>1</sup> Two ‘Military Veterans’ were joined by their wives for the interview. They also shared their experiences with benefits.

# Research Methods

## Participant demographics

Research consisted of one-to-one interviews with a total of 20 participants. Participants were based in Glasgow, Edinburgh, Aberdeenshire, Perth, Erskine, Dundee, Falkirk, Kilmarnock and Fife. No one in the 'Homeless' subgroup was homeless at the time of interview, rather they had experienced periods of homelessness prior to interview.

**Table 1: Participants by area**

Geographical area	Total no. of participants
Glasgow	5
Edinburgh	5
Kilmarnock	1
Falkirk	1
Fife	1
Perth	1
Dundee	1
Aberdeenshire	2
Erskine	3

Two participants were in the 25 to 45 age group, and 18 in the 45 to 70 age group at the time of interview. One research participant was identified as Minority Ethnic. All participants were living with at least one physical or mental health condition.

**Table 2: Physical and mental health conditions**

	Physical	Mental	Both	Total no. of participants in sub-group
Veterans	5	6	4	7
Homeless	6	6	6	7
HIV/Hep C	5	3	3	6



Participants claimed, or had previously claimed the benefits listed in below.

**Table 3: Type of benefit claimed**

<b>Benefit</b>	<b>Total no. of Participants</b>
Universal Credit	8
Personal Independence Payment	12
Carers Allowance	3
Job Seekers Allowance	2
Employment Support Allowance	10
Housing Benefit	3
Incapacity Benefit	1
Disability Living Allowance	4
Attendance Allowance	1
Council Tax Benefit	2
Income Top Up	1
Severe Disability Allowance	1

## **Interview method**

All interviews were undertaken by an independent research company, 'Mark Diffley Consultancy and Research', commissioned by the Scottish Government. Initially, interviews were carried out face-to face between October 2019 to February 2020 before pausing due to the COVID-19 pandemic. Thereafter, they were conducted from July to August 2020 via video conferencing.

Interviews lasted up to an hour in length and were carried out between a member of the research consultancy and the individual participant. The exception was when a participant brought along their spouse, who interviewed on the participants' behalf, most usually due to their debilitating health conditions.

Participants were recruited via stakeholder organisations relating to each sub-group (for example, Shelter Scotland for the Homeless). Demographic quotas were not used in the recruitment of participants, although where possible a mixture of genders and ages were sought.

All research carried out was compliant with Social Research Association Ethical Guidelines. Mark Diffley Consultancy and Research did not disclose the identities of participants to Scottish Government researchers, while all participants consented to participate after having been informed of their rights, including those relating to the General Data Protection Regulation (GDPR). A £20 gift voucher was offered as an incentive for taking part. Some participants who took part did not accept the monetary incentive.

## **Research Questions**

Participants were asked questions about their experiences and perceptions of:

- Social security services in general – including their awareness of social security services, the perceived ease/difficulty of accessibility to services, the need for help to access these services, their perceived eligibility for claiming benefits and what benefits they receive currently and in the past.
- The current benefits system – including awareness of benefit information, experiences of providing medical evidence, and opinions on how people from diverse groups can be treated with dignity, fairness and respect.
- What the future social security system should be like – including the application process, information provided on benefits, and local delivery services.

## **Quotations**

The data provided by the research contractors, and analysed in this briefing, are summaries of interviews rather than full verbatim transcripts. Where quotation marks are used in excerpts (“...”), this indicates direct quotations of participants as

recorded by the research contractor. All other text included in excerpts represents the summarised note taking of the interviewer as below:

**He has general worries that his benefits are going to be reduced...particularly when he's heard a lot of "horror stories" on the news / internet about people having their benefit cut with no rhyme or reason.**

[Veteran participant, Aberdeen]

A list of commonly used abbreviations used in this report are found in Annex B.

## General experiences of benefits

Many of the participants lived with multiple, often interrelated physical and mental health conditions which sometimes included addictions. The impacts of such conditions went beyond loss of health. They affect areas of day-to-day life such as social relations, employability, mobility and housing security.

Due to the complex and ongoing impact of such conditions, participants across all three sub-groups often had many years' experience of claiming benefits. A few participants had experience of claiming benefits that extends across two decades, while most ranged from 2-10 years.

### Support networks and resources

Each of the three sub-groups reported a strong reliance of third sector organisations to help navigate the social security system. These organisations are credited with helping participants understand their eligibility for specific benefits; fill in benefit application forms; accompany and support participants during assessments, appeals and tribunals and generally help navigate the social security system.

A wide range of third sector organisations were credited as providing support. Citizens Advice were mentioned by participants across all three sub-groups. However, the majority of third sector organisations provided support specific to the needs of, or collective identity of, that sub-group.

Veteran participants mentioned The British Legion, Unforgotten Forces, Veterans Assist, Bravehound, and Advice Works (among others). For the HIV/Hepatitis C sub-group, third sector organisations included Waverley Care (Edinburgh based), the Terrence Higgins Trust, HIV Scotland and Quarriers. Within the Homeless sub-group, third sector organisations mentioned were Social Bite (Glasgow based), Turning Point Scotland, Cyrenians, Change Grow Live, and Safeguarding Communities – Reducing Offending (SACRO).

To a lesser extent, GPs and nurses, council workers, and Job Centre staff were among those credited with 'signposting' participants to third sector organisations, other benefit services and advising on eligibility.

Participants had mixed experiences of support from the UK government DWP. A few were positive about their use of UK government websites to inform them of eligibility, to apply for benefits, and to receive updates on their application status. However, no single research participant credited these websites and digital services alone as providing all the information and advice they needed to submit an application. They all relied on mostly third sector support.

For some participants, UK government websites were experienced as a barrier to finding out about benefit eligibility and filling in forms. Notably these participants were used to receiving information or applying for benefits and receiving updates in paper formats. Similarly, participants who had limited access to digital devices and internet connection experienced these as a barrier.

When it came to the availability and quality of face-to-face or telephone helpline services, participants were mostly negative about their experiences with DWP staff.

For a few participants, social media and the internet in general was where benefit applicants/recipients shared information on eligibility criteria and the application system.

## **Benefits claimed**

Research participants identifying as living with Human Immunodeficiency Virus (HIV) or Hepatitis C were most likely to have experience of receiving multiple benefits when compared to the other sub-groups.

Participants identifying as Military Veterans were least likely to report receiving multiple benefits (simultaneously, or consecutively) when compared to the other sub-groups.

The HIV/Hepatitis C sub-group were the group most likely to be in receipt of PIP and Employment and Support Allowance (ESA).

The Homeless sub-group were most likely to be in receipt of PIP and Universal Credit (UC).

The Veteran sub-group were the most commonly in receipt of ESA and Disability Living Allowance (DLA).

# Key challenges and barriers with the benefit system

As participants related their experiences with the benefits system, some significant themes emerged, pointing towards challenges and barriers commonly felt across the three sub-groups.

## Key themes

- Many participants indicated that finding out about which benefits they are entitled to is difficult, due to lack of awareness on where to get information. The benefit system was perceived as complex, unfamiliar and participants felt there is a lack of readily available information.
- For some, a lack of face-to-face interaction with benefit agency staff was felt to perpetuate such difficulties, as they found it difficult to navigate the benefits system online.
- Participants commonly reported that applications forms and assessment procedures were too inflexible to accommodate their individual experiences.
- The complexity of some application forms for some benefits (e.g. PIP, DLA, UC, etc.) were described as a barrier for various participants.
- Some participants felt unsure whether they were filling in forms the 'right way'. Feelings of insecurity increased participants reliance on third sector services to help fill in forms.
- Some participants felt stigmatised and discriminated against when interacting with staff from the benefit agencies.

- Some participants felt official reports, based on health assessments, were inaccurate and one-sided, and that the nuance and complexity of their medical histories were not adequately captured.
- For those who had experienced trauma and other mental health issues, health assessment staff were found to be poorly trained/ insensitive to such issues.
- For participants who had experienced the benefits system over many years, the system was described as having become increasingly complex, inflexible and inaccessible, and less able to capture complex health issues.
- Many participants were positive about the regularity with which payments were received and the delivery method (via bank account). However, gaps in payments when transitioning from one benefit to another resulted in financial difficulties (this was particularly true when transitioning to/from UC).

### **Finding out about eligibility**

The benefit system was perceived as complex and unfamiliar, with a lack of readily available information. Complexity, unfamiliarity and a lack of available information were experienced by participants as barriers to finding out about eligibility.

Many participants from across the three sub-groups found it difficult to find information about their eligibility for benefits. Complexity of the benefit system and not knowing where to look were given as reasons for this: "...the benefits system is so complicated" stated one research participant.

For some, a lack of face-to-face interaction with benefit agency staff was felt to perpetuate such difficulties, in particular they found it difficult to navigate the benefits system online.

Several participants, from each of the three sub-groups, commented on the coincidental or 'roundabout' way in which they were made aware of their eligibility



for benefits. One research participant said they were motivated to take part in the research because they felt there were others like them who are eligible for “hidden benefits”; benefits that are unpublicised and inaccessible without expert knowledge.

One research participant complained of there being no “one-stop shop” to find out about eligibility. Others related how they had been given conflicting information on eligibility criteria from third sector organisations and job centres.

A research participant with several years’ experience of claiming benefits explained that the eligibility criteria kept changing, so that they were no longer sure what they were eligible for: “they kept changing the rules on how far you could walk”.

Another research participant found that as more information about benefits moved online, they no longer found information on eligibility accessible. They described how they previously relied on a “brown envelope” coming through the post containing information that explained which benefits they were eligible for.

**[Participant] receives PIP, but only came to apply for it in a roundabout way via a welfare rights officer when he was in contact with them about something else. He had no idea he was eligible... Overall, he feels that the system is very complicated and that unless you have someone guiding you through it, you’re liable to not be getting everything you’re eligible for.**

[Homeless participant, Glasgow]

**Citizens Advice ...suggested that [participant] would be eligible for Severe Disablement and Carers Allowance...She was surprised as she didn’t think of herself as either severely disabled or as a carer. She was awarded both benefits....**

**...she feels that there may be many similar individuals who are eligible for benefits that are “hidden”... “that the government doesn’t publicise.”**

[HIV/Hep C participant, Glasgow]

## **Complexity of benefit application forms – filling it in ‘the right way’**

Many participants across the three sub-groups stated they found benefit applications too difficult to fill in for benefits including PIP, DLA, and UC. Reasons given ranged from the language used in benefit forms being too complex or full of jargon, to forms being too long and complicated.

There was also a strongly held perception of being a ‘right way’ and a ‘wrong way’ to fill in forms (precisely how to fill in forms the ‘right way’ was unknown to most participants). For many participants who felt unsure if they were filling in forms the ‘right way’, this increased their reliance of third sector services to help fill in forms (see section below on application forms in the veteran sub-group section for more information).

A few participants also reported that difficulties filling in forms were compounded by difficulties engaging with DWP support services. Long call waits were pointed out as a barrier to gaining help over the phone when filling in forms. Advice given by DWP advisors was also described by a few participants as being poor or unhelpful.

**[Participant] describes how she “hates the forms and the form filling” and that the process is “horrible.”**

**... Above all, she is negative because “they do not take account my personal situation.” She added: “If you word it the right way then you are fine. If you don’t then you aren’t.”**

[Homeless participant, Edinburgh]

**Although [participant] tries to fill in social security forms herself, she thinks they’ve become more complicated and at times she’s had to ask for help (from Social Bite, from Citizens Advice). Sometimes she’s been unsure what she is being asked.**

**“One question was, ‘can you understand and read written, complicated words’ or something....and one of the things underneath it says, ‘would you understand it if you were encouraged?’...if I don’t understand something, I don’t understand it...maybe explain it to me.”**

[Homeless participant, Glasgow]

### **Inflexibility, no room for nuance or explanation**

Some participants described how the rigid format of benefit application forms and assessment procedures were insufficient to accommodate information they wished to give about their individual circumstances. Across each of the three sub-groups, participants voiced concern and frustration at not being able to express, or have recorded the nuances of their individual life experiences.

Benefit application forms were characterised as being too rigid and too prescriptive in the kinds of response the DWP required. This extended to the assessment process. One research participant described how the lack of personalisation in the PIP assessment process added to their distress and frustration and they found it was difficult to respond to questions requiring very specific answers.

Some participants also felt that official reports, based on health assessments, were inaccurate and one-sided, and that their medical histories were not adequately captured.

**...[participant] felt that with a lot of the questions designed to assess her, they either weren't relevant, she didn't think they were a good way to assess her situation and / or she wasn't allowed to explain herself / any nuance in the answers (they were often yes/no questions).**

[Homeless participant, Glasgow]

**She found the assessment stressful and frustrating: the questions were difficult to answer (for example how far, in metres, can you walk?) and seemed to require very specific answers. She was worried that she might be giving the "wrong" answers and felt that the questions were very "standardised", that they didn't take individual circumstances / experiences into account.**

[HIV/Hep C participant, Glasgow]

## **Stigma: Mistrust inbuilt in the system**

While some participants feared giving the “wrong” answer in benefit applications and assessments, others saw these difficulties as DWP trying to ‘catch you out’ - purposefully making it difficult so to discourage people from applying.

For a few participants, this left them feeling stigmatised and discriminated against. Some voiced concern that the benefits system often treats claimants with suspicion. As one research participant stated, they assume you are ‘trying to “play the system”’. For others, feeling stigmatised and mistrusted was described as being made to feel less-than-human, as being deprived of dignity and respect. These feelings were notably voiced by participants who experienced the PIP assessment.

The perception of the system being rigged, alongside feeling mistrusted and stigmatised, increased participants reliance on third sector organisations to help fill out forms.

**[The participant] described dreadful experiences of claiming PIP – in his view, when claiming the benefit, the DWP “treated me like a criminal, like I was a scrounger. They don’t help people.”**

[HIV/Hep C participant, Edinburgh]

**“I felt like a 2 year old sitting there and it [PIP assessment] was like an interrogation... you’re no treated like a human being. She wasnae caring....it was like she was resentful that you’re getting benefits....you could feel it just the way she was looking...it was like, ‘why the \*\*\*\* should you get this and you’re no working’.”**

[Homeless participant, Glasgow]

## **Writing the assessment record: a one-sided process**

While a particular source of frustration for participants was their inability to express in their own terms their life experiences in application forms and during assessments, it was in relation to assessment reports that concerns were most strongly raised and precise examples given.

A few participants from the Veteran and HIV/Hep C sub-groups who had undertaken PIP and/or DLA assessments described their experience of reading assessment reports and finding them to be incorrect or not representative of their experience of the assessment (this is mentioned in more detail in the veterans sub-group section).

Each perceived that after the assessment the decision to award or deny them PIP/DLA benefit rested on information provided in these reports *only*; that reports were one-sided and based on the subjective view of the assessor during a single interaction. A notable concern was that medical evidence from GPs or mental health specialists was not taken into consideration.

Participants were critical of a social security system that does not allow for reports to be revised or co-authored by the research participant themselves or an independent witnesses, without going through a stressful appeals process.

**The report of the meeting ... did not correspond with his [the participants'] own account. In particular, he said that the nurse had described how he had shown her that he could draw up a syringe. But he said that he didn't leave his chair during the meeting and that he doesn't have syringes in the house... it was almost as if the report concerned a completely different person. However, it was on the basis of this report that he was denied PIP / was offered it at a lower level.**

[HIV/Hep C participant, Kilmarnock]

## **Long term perspective: Increasing complexity of the social security system**

Some participants had over a decade of experience of the benefits system, providing a long-term perspective on continuity and change.

For participants who had experienced the benefits system over many years, the system was described as having become increasingly complex, rigid and inaccessible, and less able to capture complex health issues.

One research participant perceived that the amount of evidence they are asked to provide has also increased, to more than they considered necessary.

Participants reported that they had increasingly found the benefits process more difficult to navigate, while, for a few participants, these changes left them feeling disengaged with DWP.

**As someone who has had to claim benefits of varying kinds on and off over many years, his view is that the process has becoming “increasingly problematic” – in his view in the last five years “it has got more and more difficult to claim over time”. He says that you now need more forms of ID, passport, driving licence and bank account details – [i]n his view this [is] “over the top” and leads to “disengagement” with the DWP.**

[Homeless participant, Edinburgh]

### **Mental health and training of assessment staff**

For participants who had experienced trauma and other mental health issues, health assessment staff were found to be poorly trained or insensitive to such issues.

PIP assessments were a particular source of grievance. Several participants described how assessors, rather than base their assessment on medical or psychiatric evidence provided by medical professionals, made their own assessment of the participants' mental health status within the assessment.

The assessors were perceived to be unqualified 'just nurses or assistants'. Yet participants felt that the outcome of an assessment was based on these one-off encounters.

Several participants detail how assessors pushed them, during the assessment, to justify how or even if they had a mental health condition. One research participant reported having several panic attacks during the assessment. This coincided with the participant feeling he had to re-tell stories of personal trauma to justify his PTSD diagnosis.

Another research participant reported how, during the assessment, she was told it was necessary to undergo a physical examination with a male assessor. As a survivor of childhood sexual abuse, the participant found the examination upsetting, more so as her request to be examined by a female assessor was denied (see below in the Veteran sub-group section for more detail).

Health assessments left many participants feeling humiliated and degraded, and in some cases, triggered additional traumatic experiences.

**“All the questions...it was one of the most humiliating, degrading things that you can do to a human being...question their mental health. These people that are assessing you are not even qualified doctors or mental health workers...these are just nurses or assistants...it’s wrong.”**

[Homeless participant, Glasgow]

## **Payments and financial hardship**

When participants received benefit payments they were usually happy with the regularity of payments and the delivery method (with the exception of the homeless sub-group).

However, problems reportedly occurred in relation to UC. Notably, financial hardship was experienced during trials when UC was first rolled out, or when participants moved to UC from another benefit. This was largely due to the waiting time from a previous benefit being cut to receiving their first UC payment (reported to be between 8-14 weeks).

Participants described having experienced financial hardship due to the above factors, despite some reporting that they received advanced payments. Moreover, a few participants explained that in the 'early' days of UC, payments were 'chaotic', 'slow' and 'irregular'.

For some participants, they feared being moved over to a different benefit type, notably PIP, because they anticipate this will bring financial hardship.

**He has general worries that his benefits are going to be reduced (for example when he's moved over to PIP) since money is already very tight, particularly when he's heard a lot of "horror stories" on the news / internet about people having their benefits cut with no rhyme nor reason.**

[Veteran participant, Aberdeenshire]



## Enablers and views on improvement of the benefit system

Based on the lived experiences of participants across all three sub-groups, positive experiences (enablers) around the benefit system were also identified. Some participants also had views on how the system can be improved.

While the experiences of sub-groups differed in significant ways when experiencing barriers to benefit uptake, there was greater commonality in the enablers expressed by participants. The most common suggestions and enablers, as expressed by participants from across the three sub-groups, are detailed below.

### Eligibility criteria

A few participants from across the three sub-groups wanted it to be easier to understand what benefits they were eligible for.

Several participants called for more 'joined-up' services; ones that connected community and medical services to benefit agencies. One research participant suggested that GPs should signpost patients to agencies that can advise of benefit eligibility. Another suggestion relates to community services that provide advice on how mental health and addiction issues relate to benefit entitlement.

One specific difficulty, noted by several participants in the Homeless and HIV/Hep C sub-groups, was that the eligibility criteria for certain benefits changes regularly.

**“They kept changing rules on how far you could walk. Because I didn’t use a stick that counted against me.”**

[HIV/Hep C participant, Fife]

Participants' understanding of their eligibility was hampered by these changes, and therefore few participants called for eligibility 'goalposts' as one research participant put it to become fixed for longer periods of time.

In so doing, they suggested this will reduce the complexity, and increase the certainty of, the social security system for benefit applicants.

**It should be easier to find out what benefits you might be eligible for (the respondent's wife has only fairly recently been aware of carers allowance / budget). She thinks that the GP should be the signposter to other agencies.**

[Veteran participant, Dundee]

**There is a sense that the goalposts for criteria in terms of what can/can't be claimed changes regularly and is too complex; therefore, the suggestion is that there should be a prolonged period where criteria do not change.**

[Homeless participant, Edinburgh]

## **Simplification of application forms**

Most participants called for application forms to be made simpler; use more straight forward and clearer language (no-jargon); and to be easier to fill in. PIP, DLA and CA forms were specifically mentioned as being too difficult for the applicant to fill in.

As for the simplification of language, participants from across the three sub-groups called for communication styles that were compatible with various health or disability statuses.

Some participants also wanted application forms to be simplified by having their information or evidence from previous applications stored, so to make multiple applications quicker.

If forms cannot be simplified, several participants requested that more services be made available to help people fill them in (see section below on ‘Joined up services’ and ‘Channels of communication’).

It is notable that for a handful of participants in the HIV/Hep C and Homeless sub-groups, they wanted forms to be simpler while also being able to capture the individuality and nuance of their individual experiences.

For these participants, simplification may not just mean simpler language or shorter or auto-fill forms. It may also mean forms that enable them to tell their individual story; where participants do not feel put off by the fear of filling in forms the ‘wrong way’.

**“Make it easier for people to access computers...all the jargon and all the \*\*\*\*\* that goes with it, forms to get filled out...I’m dyslexic and if I lost it and someone asked me to go and do all that today, I’d just be suicidal, my brain just couldn’t cope with it...”**

[Homeless participant, Glasgow]

**It shouldn’t be so difficult to fill in the forms. Either you make the forms easier and more straightforward or you provide people with help to fill them in.**

[Veteran participant, Dundee]

## **Assessments: Medical evidence**

Some participants across the three sub-groups called for GP records and medical evidence to be used as the basis of benefit assessments.

Largely, these views were voiced in response to negative experiences with PIP assessors; for those that were left feeling humiliated, stressed or disbelieved.

Those who identified as sufferers of PTSD or trauma-related mental health issues especially wanted GP or expert medical evidence to replace the need to communicate in-person their traumatic experiences in front of assessors.

A few participants thought that their benefit application was refused on the basis of an incorrect or misinformed medical assessment. This was especially so for participants who subsequently went through a successful appeals process.

Rather than have assessments based on one-off observations, participants therefore called for GP and expert medical reports to weigh heavier, as evidence, than the judgements of a single assessor.

**[Participant] describes these current assessments as “very stressful” and “humiliating” and would be very keen to see a new system get rid of them. He thinks that reports from his doctor and HIV consultant should be sufficient to be entitled to benefits.**

[HIV/Hep C participant, Edinburgh]

**Change assessment system – 60% of appeals win “so there must be something wrong with current process of medicals.” Appeals are “very stressful” and it can be very upsetting to get a letter saying your benefits are being cut.**

[HIV/Hep C participant, Fife]

### **Assessments: The official record**

Several participants who attended PIP and DLA assessments stated there should be joint agreement between assessor and applicant as to what was said and done in assessments.

To enable joint agreement, participants variously suggested that conversations in assessments be recorded, that there be independent witnesses to these

assessments, and that the applicant and assessor should jointly agree on the contents of the official report.

**Nurse assessments for PIP – why was the account of the meeting so different to his own recollection? who are these nurses? are their assessments the key input into decisions? Overall, a need for these – and the process around them – to become more transparent.**

[HIV/Hep C participant, Kilmarnock]

## **Renewals**

Despite some of the HIV/Hep C group stating that they experienced increased levels of stress and financial uncertainty because of the frequency by which they were being re-assessed for benefits, only one research participant directly stated that they wanted this aspect of the process to be improved. This was a suggestion of fewer renewals, so that people have greater certainty over their income for longer periods of time.

**Fewer renewals to give people certainty re their income for a longer period of time**

[HIV/Hep C, Kilmarnock]

## **Specialised training of DWP assessors and staff**

Some participants across all three subgroups wanted DWP assessors and helpline staff to be better trained to treat people with vulnerabilities, in particular those with mental health issues.

**Assessors should be highly trained to deal with vulnerable people.**

[Homeless participant, Glasgow]

**Staff – she thinks that there needs to be a “better calibre” of staff at the DWP and Job Centres, with more training on communicating and dealing with people who are in need.**

[Homeless participant, Edinburgh]

## **Joined-up services**

Many participants in the Homeless sub-group called for more joined-up services to help access and navigate social security services.

Participants suggested this could be achieved by the provision of community based hubs for finding out about benefits and receiving help with applications. This included college based workshops to teach people about the benefits system, hubs in job centres to help people navigate the system and fill in forms, as well as more outreach work targeted at people living on the streets and those with mental health issues.

A few participants from the Veteran and Homeless sub-groups also called for medical and third sector organisations to be more joined up with Social Security and healthcare services; for GPs to signpost to other agencies, and for third sector organisations dealing with mental health and addiction to provide more coherent, joined-up services with social security agencies.

**Set up hubs in the job centres and give people proper support to navigate the system and fill in the forms.**

[Homeless participant, Glasgow]

## **Channels of communication**

**Local Delivery:** many research participants were in support of local delivery services. Support was evenly spread across the three sub-groups.

Participants variously described the need for these services to be delivered by people who were caring, professionally trained, good listeners, and who based their assessments on the individual circumstances of the applicant. For some who found it difficult to travel far due to health conditions, locally-based services were described as a preferable alternative, including home visits.

A few participants who were in support of local delivery nonetheless felt they had 'heard it all before' and doubted the service would materialise.

**Online service delivery:** Several participants had a positive experience with the online services of the DWP, and called for more services to be moved online.

**Face-to-face service delivery:** However, an equal number of participants called for more human interaction via face-to-face meetings and video calls.

**Postal:** A few applicants stressed that they found the social security system more difficult to navigate and find out about eligibility since the 'brown envelope' stopped coming through their letter box. This is notably for participants who are uncomfortable with or have limited access to information technology.

**[Research participant] is very comfortable online and finds the DWP website "clear and helpful" – with that in mind he would like any new social security system in Scotland to do as much online as possible.**

**He was supportive of the concept of local delivery advisors and a home visit or phone call would be the preferred method of contact with appointments arranged online.**

[HIV/Hep C participant, Edinburgh]

**Values:** many participants across the three sub-groups wanted the social security system to treat applicants as human beings. Participants wanted the design of application forms, and the approach of individual assessors, to enable expression of individual circumstances with nuance and clarity. Moreover, participants wanted

the ability to tell social security of their individual circumstances in their own way, and to be listened to properly.

While many participants across the three sub-groups felt stigmatised by the social security system, several participants stressed that trust, believing what people tell you (including GP evidence) and not viewing people as trying to scam the system should be inbuilt into the social security system.

**“Treat people like human beings”.**

[Veteran participant, Erskine]

**Make the tribunal process less stressful (why a panel of 3 people? why can't they take the evidence that's made available – why do people have to be seen face to face? panel need to be more respectful and treat claimants as human beings).**

[Homeless participant, Glasgow]

**Assess people as people, talk to them and find out about their circumstance[s] vs using narrow criteria.**

[Veteran, Aberdeenshire]



## What's next?

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

<b>Barriers</b>	<b>Enablers</b>	<b>Action</b>
<p>The benefit system is complex and unfamiliar</p> <p>The social security system has become more complex, inflexible and inaccessible than before</p>		<p>A general duty to promote the take-up of devolved benefits is enshrined in the <a href="#">Social Security (Scotland) Act 2018</a>. Social Security Scotland and the Scottish Government to date have published <a href="#">two take-up strategies</a> that set out all the activity and engagement being undertaken to ensure awareness of benefits improves.</p> <p>Social Security Scotland will build on these findings by carrying out further research to identify and explore how best to communicate and market benefits to hard-to-reach and marginalised groups. The results of this research will be used to develop bespoke communication and engagement plans to support communication activity.</p>

		<p>The findings from this research have been fed into the consideration to implement a joined-up approach to improve access to information and support, and the importance of providing a range of communication options, in the work to develop Scottish Carer’s Assistance, the Scottish replacement benefit for Carers Allowance. The intention is for the new benefit to reach more carers, and help carers find out about the wider support which is available to them.</p>
<p>Difficulty finding information</p>		<p>Social Security Scotland has introduced inclusive communication approaches in all its work; working towards clear and accessible information, and a clear and transparent explanation of the eligibility criteria for each application form.</p>
	<p>Various channels of communication and support</p> <p>Preferences to local delivery services</p>	<p>For the benefits that have been and will be devolved to Scotland Social Security Scotland will offer a range of ways to apply for the benefits they deliver including online, telephone, paper-based or face-to-face. Further applicants will be offered support when applying for disability benefits. This multi-channel approach will ensure that those who cannot or choose not to</p>

	<p>Joined up services to help access and navigate social security services</p>	<p>adopt digital methods will not become isolated through technology.</p> <p>The findings on the preference for face-to-face support will be fed into the development of the Local Delivery service in local communities across Scotland. This service will be person-centred by providing local presence to meet people’s needs in key locations where clients currently attend. Local delivery staff will provide pre-application advice and support to encourage people to take up the payments they are entitled to.</p>
<p>Stigma built in the system</p>	<p>Specialised training of DWP assessors and staff Trust inbuilt in Social Security System</p>	<p>Social Security Scotland and Scottish Government have gone to great lengths to ensure that fairness, dignity and respect are embedded in the new system. <a href="#">Our Charter</a> was co-designed to ensure that what a good system looks like is set out in full. This system includes the need for staff to be knowledgeable and empathetic. The <a href="#">Charter Measurement Framework</a> (also co-designed) monitors and reports on a yearly basis the progress being made against the Charter.</p>

<p>Complexity of the application forms (prescriptive, rigid)</p> <p>Rigid format of application forms and assessments</p>	<p>Easier understating of benefit eligibility and advise (using a joined up approach)</p> <p>Simplification of application forms</p> <p>Applications forms should allow explanations of individual circumstances</p> <p>Simplification of by having information or evidence from previous application stored</p>	<p>Social Security Scotland has introduced inclusive communication approaches in all its work including application processes, all systems and client/staff interaction.</p> <p>Further, the design of forms and application processes are undertaken in 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>Storing information from clients to prevent duplication is addressed by a new practice to gather information. This practice will focus on Social Security Scotland being able to proactively store information from the client since the start of application when that is possible. This will reduce the burden on the applicant.</p>
<p>Health assessment staff are poorly trained or insensitive</p>		<p>Decision Making Guidance and Agency Medical Guidance will be developed with stakeholders. They will fully capture the</p>

<p>to mental health conditions and trauma</p>		<p>impact of living with mental health conditions, other fluctuating conditions, and learning disabilities.</p>
<p>Assessment reports are one sided, subjective and inaccurate</p>	<p>Health assessment reports should be a joint agreement between assessor and applicant</p> <p>GP records and medical evidence weighted heavier on assessments</p>	<p>These suggestions are aligned with the approach to supporting information being implemented by Social Security Scotland. This approach will consider using supporting information from the medical profession.</p>
<p>Strong reliance of third sector organisations to help navigate the social security system</p>		<p>Scottish Government has published two <a href="#">take-up strategies</a> that include engaging with advocacy organisations to address barriers to benefit take-up. The findings from this research will inform a targeted approach with these specific groups for the implementation of interventions committed to in the Benefit take-up Strategy.</p> <p>The findings from this research will be used to inform stakeholder engagement which communicates changes on</p>

		<p>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>Payments and financial hardship due to long waiting times</p>		<p>Social Security Scotland has implemented a short-term assistance payment to cover the income reduced or stopped during the process of redetermination or appeals of disability payments. This will ensure a client is not discouraged from challenging that decision and they access administrative justice by having to manage, for a period, with a reduced income.</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.

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

Mark Diffley Consultancy and Research (now Diffley Partnership) is doing a second wave of fieldwork with Vulnerable Groups which we expect will be completed in the winter of 2021/22. Similarly to the recruitment strategy applied in the first wave, participants are being recruited through stakeholder organisations and in some cases via public sector organisations. The second wave of interviews with vulnerable groups will include participants identified in the previous sub-groups and a further sub-group (to include prisoners, ex-offenders or their close family members; and participants with community sentences).

# Annex A: Main challenges concerning specific sub-groups

Participants highlighted a range of issues which represent challenges and barriers for accessing benefits. Some of these were more common for specific sub-groups.

## Homeless

### Key themes

- Of the three sub-groups, the homeless strand reported experiencing the least amount of help from third sector organisations.
- Many participants related how their mental health issues were further exacerbated by, and posed a significant barrier to, their interactions with DWP and assessment staff.
- PIP assessments were notably credited as leaving participants feeling stressed, stigmatised and stereotyped. Assessment staff were perceived as having inadequate training in mental health issues.
- One respondent noted that not having a mobile phone, or the ability to regularly check social security websites and receive updates and appointment details was a significant barrier to accessing social security services for those living on the streets.<sup>2</sup>
- Some of this sub-group explained that lump sum payments posed difficulties with financial budgeting.

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<sup>2</sup> Of note, no participants interviewed were currently living on the streets. This remark was made when a participant reflected on their past experience of living on the streets.



## Support networks

Of the three sub-groups, the Homeless group reported experiencing the least amount of help from third sector organisations in terms of; navigating the social security system; understanding eligibility; filling in application forms; and attending assessments and tribunals.

Almost half of homeless participants reported receiving no or little help from third sector organisations when engaging with social security services.

**Table 4: Third sector engagement across the three sub-groups**

	No. of third sector organisations engaged with	Total no. of participants in sub-group
Veterans	12	7
Homeless	7	7
HIV/Hep C	14	6

**Information – [participant] says that she had to be “entirely self-taught” when it comes to finding out about what she was entitled to from the benefits system, adding that there was “no help at all from government or other agencies.” She thinks there was no choice for her because “you have to do it yourself as no one else will help you.”**

**Application forms – PIP application form “was painful to fill in” – she tried to get an at home appointment for advice and support but this was refused.**

[Homeless, Edinburgh]

## Mental Health

All participants in the Homeless sub-group were living with longstanding mental health issues (some significant). More than half of homeless participants related in the interview how their mental health issues were further exacerbated by, and posed a significant barrier to, their interactions with social security services. This

included when they had to; fill in forms; fulfil job search criteria for Job Seekers Allowance and attending assessments.

One homeless participant noted that those living on the streets with mental health issues were the most vulnerable, yet least likely, to access social security services. They explained that complexity of the process for seeking social security benefits, combined with their limited access to mobile phones and/or ability to travel, led to their difficulties accessing social security services.

As with participants across all three sub-groups, several homeless participants were left feeling intimidated, humiliated, disbelieved and, for some, dehumanised in a PIP assessment because of the way in which their mental health was discussed.

**“The benefits system just now is set up where it’s so hard...it’s confusing when you go to deal with it and my brain can’t cope with that..all the websites...to find out information...you hardly get a brown letter now just explaining about your benefits.....To me it’s just a pain in the \*\*\*\*.”... “I know boys in the toon that will just no go near a brew (job centre) because they’re just like, ‘I cannae deal with it, I cannae deal with it’ and that’s how they’re oot...their oot in this weather... it’s hard work, especially with people with mental health problems...it’s really hard to take in”.**

[Homeless, Glasgow]

**“These people that are assessing you are not even qualified doctors or mental health workers....these are just nurses or assistants....it’s wrong... I wasnae treated like a human being....it was like ‘you sit there because you’ve got a mental illness, or you’ve got AIDS’ so you’re put in a \*\*\*\*\* box and you’re no treated like a human being...”**

[Homeless, Glasgow]

### **Accessibility**

All participants at the time of interview lived in temporary or private accommodation. However, one homeless participant explained that for those living on the streets, their lack of accommodation or access to communications technologies were substantial barriers to accessing social security services.

**“The system...is bonkers...how many homeless people have got a mobile ‘phone that they can go and check it? The majority of the ham and egggers, which is a beggar, they get up to go to the library to do their job search, they’re going to lose their pitch.”**

[Homeless, Glasgow]

## **Payments**

Almost half of the Homeless sub-group, all of whom struggled with substance abuse, explained that lump sum benefit payments posed difficulties with financial budgeting. One participant explained that lump sum payments were too difficult to manage given their addictions. Another, who identified as a recovering alcoholic and cannabis user states “money has always burned a hole in my pocket”.

Each wanted more regular payments spread across the month.

## **Veterans**

### **Key themes**

- Participants felt there was a ‘right’ way to fill in application forms that was unknown to them. Some felt the forms were designed to ‘trick you’ into filling them out incorrectly, to stop people making successful claims. This resulted in greater perceived reliance on, and greater use of, third sector organisations to help fill in forms the ‘right’ way.
- Health assessments were felt to be too rigid to enable participants to adequately articulate their complex mental and physical health problems.
- Participants were strongly critical of the PIP assessment and the impact it had on their mental health. Participants variously reported feeling “humiliated” and “disbelieved” by assessors, while GP/psychiatric diagnostic evidence of Post-Traumatic Stress Disorder (PTSD) were not taken into account.

- All participants who attended a PIP assessment felt the official report bore little or only partial relation to what had been discussed and observed during the assessment. A few felt powerless to challenge the record (without going through a stressful appeals process).
- For those who successfully went through the PIP appeals process, each were supported by third sector organisations. Several expressed their inability/unwillingness to go through the stress of an appeal/tribunal without this support.

### **Application forms**

All but one veteran participant identified as living with PTSD or a trauma related mental health disorder. Most veteran participants also lived with a long-term physical health condition, including amputations, motor neurone disease (MND), heart problems, diabetes and asthma.

As with the homeless group, some veterans explained how mental health difficulties exacerbated difficulties in filling in forms and navigating the social security system.

The vast majority of veteran participants cited at least one third sector (largely veterans) organisation for helping them fill out forms. Third sector organisations include Bravehound, Veterans Assist, CAB, the Gordon Rural Action Group, Unforgotten Forces, British Legion and Blesma.

The overwhelming perception, shared by participants, was that without third sector help they would have struggled in filling in forms.

Almost half of participants felt there was a 'right way' to fill in forms that would result in a successful application, though what this 'right way' comprised of was unknown to them.

Some felt the forms were designed to 'trick you' into filling them out incorrectly, to stop people making successful claims. This further increased participants perceived

reliance on, and greater use of, third sector organisations to help fill in forms the 'right' way.

**... filling in the forms was stressful and she [wife of Veteran] felt as if she needed to fill them in in a really precise way... Generally, the respondent feels that it's made difficult on purpose and that some people drop out of the process. Without the help of Blesma, they both felt that they wouldn't have known how to fill in the forms the right way.**

[Veteran, Dundee]

### **Assessments**

Veteran participants were strongly critical of the PIP assessment and the impact it had on their mental health. Participants were variously left feeling "humiliated" and "disbelieved" by assessors, while GP/psychiatric diagnostic evidence of PTSD was reportedly not taken into account.

Almost half of veteran participants noted that assessment processes (notably for PIP and DLA) were not adequately designed or conducted to capture, assess or cater for the complexity of their mental and physical health problems.

One veteran participant couldn't understand why they had been given 'zero points' in one of the PIP assessment report sections, it 'didn't seem to reflect his reality.'

Another complained that in the DLA assessment they were only asked 'yes/no' questions; that they were given no chance (or choice as to how) to explain their individual circumstances.

One veteran participant claimed that the assessor asked if he was 'friends with his doctor'. The participant interpreted this as the assessor not trusting what the doctor said. They said the assessor implied they had "cooked up", that is falsified the evidence between them.

The perception that medical evidence, provided by GPs and mental health professionals (not aligned with DWP), was mistrusted, or disregarded, ran throughout veteran participant interviews who had attended the PIP assessment.

Troublingly, several described how the rigidity of the PIP assessment procedure meant that they were forced into undergoing experiences that triggered stress, anxiety, and in one case a panic attack.

For a veteran's wife (previously mentioned) who found the physical assessment upsetting, due to being a survivor of childhood sexual abuse, the only sign of accommodating her anxiety, she recalled, was for the male examiner to offer her 'a minute "to pull herself together"'.

Another veteran participant reported how medical evidence supplied by his GP (provided by his GP so that he didn't have to go into detail on issues he found upsetting) was not taken into account during the assessment. Rather, the PIP assessor repeatedly questioned - "badgering" as he described it – the legitimacy of his PTSD diagnosis. This, he recalled, caused him to go into some traumatic details, causing worry that flashbacks would be triggered. During a 2.5 hour PIP interview this participant experienced two panic attacks which resulted in him becoming incontinent. The participant stated that little was done to help him recover his dignity.

Only one veteran participant who received Employment and Support Allowance (ESA) didn't have a negative experience of an assessment. This, they explain, is because the assessor had experience of armed forces veterans and he was 'waived through' the assessment.

**...[participant] mentioned experience of being assessed for DLA when a doctor/assessor came to his home. [Participant] reported that individual had sat with his back to him and asked him very direct questions to which he was only to answer yes / no to (no room for any explanation of his circumstances or recognition of nuance or complexity in how he might want to answer).**

[Veteran, Perth]

## PIP assessment report

Most veteran participants applied for PIP, while over half attended an assessment. For each research participant who attended a PIP assessment, they felt the assessment report bore little, or only partial relation to what had been discussed and observed during the assessment.

Veteran participants reported that assessment staff prioritised what they perceived as irrelevant measurements and assessment criteria for mental health status, such as their personal appearance. Moreover, that assessors did not take into account GP or psychiatric diagnostic evidence. Rather, they judged assessment reports to be based on the one-off, subjective observations of an assessor.

Several veteran participants complained about the contents of assessment reports conducted by DWP contracted nurses or medical assessors in their own homes. One stated that their assessment report included two pages of specifics that he wasn't assessed on.

**The report from the assessor didn't appear to bear much relation to what had been discussed in the assessment: neither the respondent nor the support worker felt it reflected his situation at all...**

[Veteran, Perth]

**The nurse assessor came to his house and was charming and friendly but... the report... appeared to doubt the medical evidence that he had submitted ... and also included two pages of specifics that he said he wasn't assessed on (...he had two witnesses in the room to vouch for him).... [He has a] strong suspicion that the report appears to have been fabricated to serve the benefits system's aims vs those of the people that need support.**

[Veteran, Erskine]

## **Stress of PIP Appeals Process**

For those who felt the assessment record poorly reflected their circumstances, many felt powerless to challenge the record (without going through a stressful appeals process).

For those who successfully went through the PIP appeals process, each were supported by third sector organisations. Several veterans expressed their inability or their unwillingness to go through the stress of an appeal/tribunal without this support.

The anticipation of the appeals process being stressful was, for all veteran participants who spoke on the subject of appeals, a significant barrier to accessing the benefit.

One veteran participant described rumours and reports from friends and acquaintances about the PIP appeals process. They suggest the benefit agency systematically denies the benefit on first application, while making the appeals process stressful to put off eligible applicants.

**During the [PIP] assessment process ... No attention appeared to have been given to official documents from GPs. ...Rejected for PIP twice...**

**Encouraged by a support worker to appeal but respondent wasn't sure if she could go through with it. However, she did with support, decision was reversed and the tribunal judge told her that she had a clear case and payments were backdated. It felt as if they had gone through an arduous process for nothing and it should have been obvious from the start that they were eligible.**

[Veteran, Erskine]

**[Participant] heard very bad reports about PIP assessments from friends and acquaintances. Specifically, that benefits seem to be being denied only to be reinstated on appeal (if the individual has felt able to appeal) but only after having caused significant stress and sometimes, hardship.**

[Veteran, Aberdeenshire]



## HIV / Hepatitis C

### Key themes

- Participants felt that benefit application forms and assessments did not equip them to communicate the variability and considerable fluctuation of health conditions experienced by many of the HIV/Hep C participants.
- Many participants found application forms for certain benefits (PIP, DLA, Carer's Allowance (CA)) too difficult to fill in without assistance from third sector organisations.
- Most participants had attended the PIP assessment, while some had also attended the PIP tribunal. All felt the assessment and or tribunal was stressful and humiliating.
- A few participants variously felt the starting assumption in the PIP assessment was that they were treated like 'scammers', 'scroungers' and 'criminals'.
- Some participants reported DWP and assessment staff to be poorly trained and unable to help, or adequately assess their individual circumstances.
- Several participants felt that the renewals process for certain benefits (that is Employment and Support Allowance (ESA)) was becoming more regular, and that this caused greater financial uncertainty and stress.
- Financial stress and hardship was experienced by most participants, as they had experienced gaps and irregular benefit payments. This occurred with UC payments, and also with a mandatory reconsideration when a respondent was moved from DLA to PIP.

### Fluctuation of health condition

When claiming for benefits, participants in the HIV/Hep C sub-group were most likely (out of the three sub-groups) to find it difficult to quantify or to adequately express their disability/health status in application forms and assessments.

Notably, a few participants felt that benefit application forms and assessments did not equip them to communicate the fluctuation of health conditions experienced by many of the HIV and Hep C participants.

As one research participant said, benefit application forms were ‘blunt instruments’ to assess their health issues. They found questions too rigid, too difficult to answer ‘appropriately, and in full, given...his health fluctuates quite considerably...’

This resulted in participants fearing that benefits would be taken away because the ‘system’ did not understand the fluctuating health status of those who live with, and are treated for, HIV/Hep C.

**[Participant] has always found access to statutory services hard, particularly when he was very ill – “you have good days and bad days and sometimes if you are having a really bad day you don’t feel able to go which is a problem.”**

[HIV/Hep C, Fife]

**...forms nowadays are more standardised and there are fewer questions that he feels he can answer appropriately, and in full, given his health issues. ... He... thinks it is difficult to convey that his health fluctuates quite considerably because of the nature of HIV and it can cause him some concern that benefits may be taken away / stopped without the system understanding this.**

[HIV/Hep C, Kilmarnock]

### **Application forms and third sector organisations**

As with participants from other sub-groups, HIV/Hep C participants reported difficulties with forms being; too ‘difficult’; their being the expectation that there is a

'right way' to fill in forms '(that is mostly unknown to applicants)'; too rigid to accommodate individual circumstances or complex health conditions.

Half of HIV and Hep C participants found benefit application forms too difficult to fill out without help from third sector organisations. This applies to PIP, Disability Allowance (DLA) and Carer's Allowance (CA).

Participants reported that the following third-sector organisations helped them fill out forms; Citizens Advice Bureau, Terrance Higgins Trust, Waverley Care and HIV Scotland.

**He was grateful for the advice [of the Citizens Advice Bureau] to make sure that he was filling [application forms] ... in the right way: he always has a feeling that he'll be caught out by not answering the questions in the way that's expected (but that is mostly unknown by applicants).**

[HIV/Hep C, Kilmarnock]

### **PIP assessment**

Most participants had attended the PIP assessment, while some had also attended the PIP appeals tribunal. All felt the assessment and tribunal were stressful and humiliating.

One research participant described the assessment as stressful and frustrating because the questions required very specific answers 'for example, how far, in meters, can you walk?', and she was worried she might be giving the 'wrong' answers.

Another research participant described assessments as "very stressful" and "humiliating", saying that reports from doctors and HIV consultants should be sufficient to entitle them to benefits. Another research participant agreed, describing the PIP assessment as 'intrusive', as a "dreadful experience". He could not understand why a doctor's report is not enough, concluding there is "no trust in the system".

As a result of PIP assessments, several participants felt that DWP staff or contracted health assessors were poorly trained, and not adequately equipped to assess their conditions.

One research participant recalled that he was denied PIP on the basis of a nurses report, the contents of which he strongly disputed. After an appeal he was awarded PIP, which prompted him to further question the nurse's assessment.

**He described dreadful experiences” of claiming PIP – in his view, when claiming the benefit, the DWP “treated me like a criminal, like I was a scrounger. They don’t help people.” ...**

**He found the assessments intrusive ... he thinks a doctor’s report should be enough for the assessment as thinks that there is “no trust in the system.”...**

**...he thinks [DWP] do not treat him like an individual, take too long to deal with issues and thinks that DWP staff are often not suitably qualified.**

[HIV/Hep C, Edinburgh]

**The respondent particularly wanted to share his experience of the assessment he received from a nurse at home as part of his PIP assessment. Although the individual was perfectly pleasant, the report of the meeting ... did not correspond with his own account. In particular, he said that the nurse had described how he had shown her that he could draw up a syringe. But he said that he didn’t leave his chair during the meeting and that he doesn’t have syringes in the house... it was almost as if the report concerned a completely different person... He says that he’d never have another assessment without having a witness with him and / or recording the meeting.**

[HIV/Hep C, Kilmarnock]

### **Payments: More regular renewals and gaps in payments**

Financial stress and hardship was experienced by most of HIV/Hep C participants, as they had experienced gaps and irregular benefit payments, or the threat of reviews and renewals. This notably occurred with UC payments.

A third of the HIV/Hep C sub-group stated that they were experiencing increased levels of stress and financial uncertainty because of the frequency of re-assessment for benefits.

Benefit reviews and renewals, explained one participant, 'are becoming more regular which means that he feels more uncertain whether his benefits will continue in the future. This leads to a feeling of vulnerability'.

HIV/Hep C participants recalled their experiences of UC; being 'underpaid' some months and 'overpaid' on others, or not receiving payment on a '5-week month'.

For others, having to go through appeals and tribunals led to weeks or months of benefits being lost, only to be re-instated on appeal.

**[Participant was] on ESA for over 10 years – medical and appeal every couple of years – “process was stressful and detrimental to my mental state.”**

**Was taken off ESA each time and he had to appeal – that involved a long process and while you are going through process you do not get full ESA.**

**Process means having to go to CAB several times for paperwork (“they were amazingly helpful”). Got through appeal each time so felt like a waste of time and very stressful.**

[HIV/Hep C, Fife]

**[Participant] also wanted to note that reviews and renewals are becoming more regular which means that he feels more uncertain whether his benefits will continue in future. This leads to a feeling of vulnerability. He reports how he had to enter a trust deed the last time his benefits were cut as he was left in an immediately precarious financial position. He mentions that he is always dreading a brown envelope arriving in the post to say that he is due for another review.**

[HIV/Hep C, Kilmarnock]

# Annex B: List of abbreviations

## Benefit Abbreviations

ESA: Employment and Support Allowance

PIP: Personal Independence Payment

DLA: Disability Living Allowance

UC: Universal Credit

HB: Housing Benefit

CTB: Council Tax Benefit

ITU: Income Top Up

CA: Carers Allowance

JSA: Job Seekers Allowance

AA: Attendance Allowance

### **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](mailto:socialsecurityexperience@gov.scot) further information.
- Cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



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