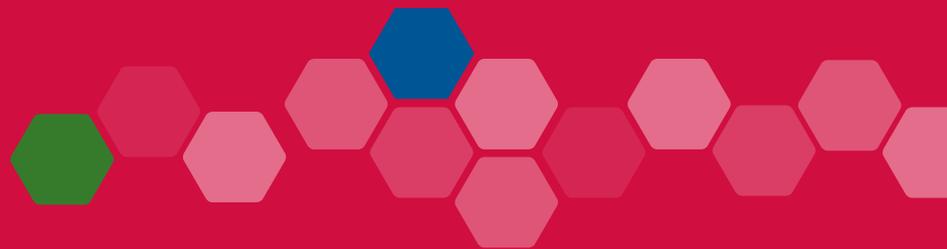




Social Security Experience Panels: About Your Benefits and You - Qualitative Research Findings



EQUALITY, POVERTY AND SOCIAL SECURITY

Executive Summary

The Social Security Experience Panels were established to ensure that the design for new social security system in Scotland is shaped by the experiences, needs and priorities of those who will use it.

This report presents analysis of the written responses and focus groups held as part of 'About Your Benefits and You', which was the first piece of research carried out with Experience Panels members.

The About Your Benefits and You research aimed to:

- find out basic demographic information about the Panels
- capture respondents' experiences of the current social security system, including what works well and what could be improved
- ask panel members their priorities for what the Scottish Government should improve in the development and delivery of the new system

1,144 panel members responded to the survey, which closed on 1 September 2017, and 274 panel members attended 35 focus groups held across Scotland.

The survey and focus groups asked about people's experiences of the existing benefits system as a whole, rather than their experiences of individual benefits. This report therefore relates to experiences of the system in general. Where respondents' comments relate to individual benefits this is noted in the text. Where individual benefits referenced are not being devolved to the Scottish Government, this is noted in a footnote for clarity.

Priorities for Improvement

Main priorities for improvement in the new system

The main priority area identified by both survey respondents and focus group participants was the importance of advice and support about claiming in accessing the benefit system. The next most common priority areas related to the process of applying for a benefit and the appeals process. A number of respondents suggested, however, that all of the listed areas were important in ensuring that applicants have a positive

end-to-end experience of the system, or that the whole system needed to be considered to ensure a positive experience for applicants and customers.

Reasons for prioritisation

The reasons respondents gave for choosing their priority areas primarily related to where their experience of the current benefits system had presented barriers or challenges.

A number of respondents highlighted the impact that these barriers had on them whilst applying for benefits, including financial and health impacts.

A number also highlighted the importance of a holistic and joined up approach to providing information, advice and support to applicants. Respondents spoke about the importance of the new system being user-focussed and one which listens and responds.

What Works Well

Friendly, Helpful and Knowledgeable Staff

The biggest factor contributing to good experiences of the current system was when staff were polite and friendly. The manner of DWP staff members and assessors was often noted when participants spoke about having a positive experience. In particular, it was important to respondents when staff showed empathy and understanding. It was also noted when it was clear that staff, particularly assessment staff, has knowledge of their condition.

Benefits Providing Support and Independence

In general, respondents recognised the value of the benefits system as being the support to live independently and manage their condition.

Simple, Clear and Timely Processes

Where people had felt that the process was straightforward, for example a simple application form, this was viewed as a positive experience.

Similarly, respondents spoke of good experiences where things were done quickly.

Flexible Approaches

People also spoke positively when the system met their needs. For example, for disability benefits including Personal Independence Payments and Employment and Support Allowance¹ respondents described positive experiences where they were offered flexibility around having assessments at home or not at all contributed to positive experiences.

Overall Negative Experiences

It is important to note, however, that a large number of survey respondents and focus group participants were not able to give any examples of where things worked well in their experience.

What Could be Improved

Inflexibility of the Current System

Respondents often spoke about experiences that highlighted an inflexibility in the current system. This included no choice in how application forms are completed or communication channels. This is particularly difficult for those with mental health conditions or conditions that make certain types of communication impossible. Practical barriers also included being expected to travel to assessment centres, short notice for assessment or tribunal dates, short timescales for completing documentation and unwillingness to meet care or support needs for people with disabilities.

Lack of Transparency

Respondents also spoke about issues that arose from a lack of transparency in the system. A lack of clear information on what to expect from processes and long wait times without information was described as leading to feelings of powerlessness when navigating a difficult process. In the context of a lack of information, respondents often spoke

¹ Please note Employment and Support Allowance is not being devolved to the Scottish Government.

about finding out about the system from informal networks and the experiences of others. Often this increased anxiety around interacting with the system.

Lack of Trust

A strong theme emerged around distrust in the relationship between the DWP and service users. Participants often spoke about a distrust of the DWP and the benefits system, but also that they felt distrusted by DWP staff. Participants spoke regularly about feeling like they were 'on trial' and that the presumption was that they were claiming benefits fraudulently.

Impact on Users

The impact that interacting with the system had on people was clear in the responses to the survey and focus groups. On the whole, the process of applying for benefits was often a source of stress and anxiety and participants feared having to go through the process again.

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Introduction

The Scottish Government will soon become responsible for some of the benefits currently paid out by the Department for Work and Pensions (DWP). As part of work to prepare for this change, the Scottish Government has set up the Social Security Experience Panels with people who have recent experience of benefits currently delivered by DWP, to help design a new social security system with the people of Scotland. The Panels will run for 4 years and are currently made up of more than 2,400 people with recent experience across the benefits which will be devolved to Scotland.

This report presents an analysis of the focus group and written responses within 'About Your Benefits and You' which was the first piece of research carried out Experience Panels members.

About Your Benefits and You Research

The About Your Benefits and You research aimed to:

- find out basic demographic information about the Panels
- capture respondents' experiences of the current social security system, including what works well and what could be improved
- ask panel members their priorities for what the Scottish Government should improve in the development and delivery of the new system

1,144 panel members responded to the survey, which closed on 1 September 2017, and 274 panel members attended 35 focus groups held across Scotland. This report provides an analysis of how respondents described their experience of the existing system in the focus groups and written comments in the survey, and their priorities for improvement in the new system.

Respondents tended to speak generally about their experience of the system as a whole in the survey and in focus groups. When information relates to specific benefits this is made clear in the report. Where individual benefits referenced are not being devolved to the Scottish Government, this is noted in a footnote for clarity. These findings will be used to develop a work plan with the Experience Panels, based on the priorities that they have identified. A full overview of questions is available at [Annex A](#).

A previous, quantitative report [published](#) in November 2017 looked at the tick-box survey data, including respondent demographics, how respondents

rated their experience overall, and their priorities for improvement in the new social security system.

Background

The Social Security Experience Panels were established to ensure that the design for new social security system in Scotland is shaped by the experiences, needs and priorities of those who will use it. Over the course of the development and introduction of the new system, panel members will participate in research and service design activities to help Scottish Government develop a system that works and that can be continually improved.

The Panels are made up of more than 2,400 people in Scotland with direct, personal experience of the current social security system. This includes individuals who have claimed themselves, as well those who have supported others.

Over the summer of 2017, panel members were invited to participate in the 'About Your Benefits and You' research.

Report Structure

This report is split into three main chapters:

- **Chapter 1:** [Priorities for improvement](#)
- **Chapter 2:** [What works well](#)
- **Chapter 3:** [What could be improved](#)

Chapter 1: Priorities for Improvement

Introduction

This chapter considers responses relating to the survey questions “What are the top three things that the Scottish Government should improve about the benefits system?” and “can you explain why you chose these as the most important?”. Focus group participants were also asked to discuss these questions as a group.

The chapter outlines the priorities which were reported in the [research findings](#), published in November 2017, as well as providing more detail on the responses of those who identified “something else” as a priority. It also considers the reasons given by responses for their choices of priority areas. These included:

- Lack of advice and support
- Impact on applicant
- Whole system improvement

Key points

Main priorities for improvement in the new system

The main priority area identified by both survey respondents and focus group participants was the importance of information and advice in accessing the benefit system. 71 per cent of respondents rated this within their top three priorities. The next most common priority areas related to the process of applying for a benefit and the appeals process. A number of respondents suggested, however, that all of the listed areas were important in ensuring that applicants have a positive end-to-end experience of the system, or that the whole system needed to be considered to ensure a positive experience for applicants and customers.

Reasons for prioritisation

The reasons respondents gave for choosing their priority areas primarily related to where their experience of the current benefits system had presented barriers or challenges.

A number of respondents highlighted the impact that these barriers had on them whilst applying for benefits, including financial and health impacts.

A number also highlighted the importance of a holistic and joined up approach to providing information, advice and support to applicants.

Priorities for improvement in the new system

As reported in the tick-box survey [research findings](#), published in November 2017, we asked respondents to tell us about their priorities for the Scottish Government to improve in the new social security system. 71 per cent of respondents to this question rated “advice and support about claiming” within their top three priorities. Other priorities included “applying for a benefit” and “having a claim reconsidered or going to appeal.” Table 1 outlines the priorities listed by survey respondents. This prioritisation is also reflective of the response from focus group participants.

Table 1: Priorities for improvement (n = 1,111)*

	% respondents
Advice and support about claiming	71%
Applying for a benefit	52%
Having a claim reconsidered or going to appeal	45%
Being kept up to date about your claim	44%
General enquires about benefits	24%
Being told the result of your application	18%
Making changes to your information after the result	13%
Making a complaint	10%
Something else	2%

* figures relate to the proportion of complete responses which listed the area within their top three priorities for improvement. Figures therefore do not add up to 100%.

Respondents who selected “something else” were asked to describe what this priority was. The analysis of these responses highlighted a number of key themes.

Many of these respondents described improvements they felt were needed within the assessment process for Personal Independence Payment (PIP). This included themes relating to the provision of evidence about their condition being taken into consideration in decision making, eliminating the need for reassessment of people with degenerative or life-long conditions, and the way that assessments are carried out. This is discussed at length in [Chapter 3](#).

Making sure the information on assessors reports are true and listening more to GP's and specialists who know about the conditions people have. If a GP or specialist say the person is unfit to work² or they class them as disabled that should be enough. The assessors are not aware of the people's background or daily life so how can they decide in 30 minutes. (Survey Respondent)

A number of respondents highlighted a need for improvements to the speed of application and appeal processes as a key priority.

Respondents emphasised the importance of a person-centred approach, including understanding how disabilities and health conditions can affect people differently. Some described a need for a system which is more sympathetic and treats customers with compassion, and emphasised the importance of improving the behaviour of staff.

Treat claimants with the dignity and respect they deserve. Stop sending confusing letters that do not make sense. (Survey Respondent)

A number of respondents also commented on the importance of effective communication channels, including improving the phone system to be quicker to answer, responding to email or written correspondence, and having more face-to-face support.

Respondents commented that they felt it was important that the new system doesn't use private companies within its processes, with some referencing the role of Atos in PIP assessments as a specific example.

² This refers to Employment Support Allowance, which is not being devolved to the Scottish Government.

Many of the respondents who highlighted “something else” as a priority felt that the whole system needs to be improved. Some also highlighted the importance of having clear policies, transparency and accountability within the new system.

Make tribunals more transparent and require them to reveal any contradictions that they think they find in the information provided by the claimant or that has been provided by any 3rd party. (Survey Respondent)

Reasons for prioritisation

When giving reasons for why they had prioritised certain parts of the system for improvement, the majority of survey respondents highlighted personal experiences where they had faced barriers or challenges within the system. This included experiences where their interaction with the system had impacted on their stress or anxiety levels, their mental health or had exacerbated their existing condition. Many of these issues are covered in [Chapter 3](#).

Lack of advice and support

The importance of advice and support about claiming was consistently highlighted when people explained their priority choices. Some respondents talked about the application process being confusing, and a lack of clear information about what you are entitled to.

The application system is confusing and time consuming and not individual enough. Far too many people are completely unaware of what they might be entitled to. Each benefit is paid at different dates each month making budgeting incredibly difficult for families. The system is a mess...time consuming, difficult, messy. There is nowhere to get advice on what you are entitled to...the calculators recommended are utter nonsense and are never correct. Too many families don't get what they are entitled to because they don't know what they can claim. (Survey Respondent)

Nothing is signposted, people are left to try figure out for themselves what they are entitled to claim. DWP make things so difficult throughout the process. (Survey Respondent).

A number of survey respondents and focus group participants described finding out about potential benefit entitlements through friends and family members or through medical professionals, rather than information available from the DWP, in particular when claiming benefits for the first time. Participants often spoke of finding out about benefits through 'luck' or 'by chance'.

Advice and support is needed as when I got ill health retirement at the age of 40 nobody told me about the benefit I could claim it was pure chance that I stumbled on it. I always worked and never claimed any benefits. (Survey Respondent).

Some focus group participants highlighted the importance of a holistic approach to providing support and advice, in particular in relation to the wider support available to applicants and other benefits that applicants may be eligible for.

It is just down to luck finding out about benefits you can apply for, this could be improved. Find out through friends and family. Society expects that families will take on caring responsibilities, GPs/district nurse/social workers could provide information to carers about benefits. There should be a holistic resource directory. However resources are so tight that provision is cut to the bone so you have to kick up a stink to get what you need. (Focus Group Participant).

A number of respondents highlighted the need for a more joined up approach between DWP departments, and with other services. In particular, respondents spoke about difficulties in finding out about other related things that they were entitled to. Disabled parking permits and Carer's Allowance were often given as an example. On one occasion, a focus group participant who had given up work to care for her husband found out about Carer's Allowance at the focus group.

DLA should cover everything from mobility payments to your blue badge and bus pass and you should be told about all of the other benefits you will be eligible for (Focus Group Participant)

Joined up approach between benefits and the other entitlements that passport – didn't know about bus passes, warm home discount. Hospitals etc. should play a key role in advising people – even if it's just a leaflet. There needs to be a central directory of all of the things you can access. (Focus Group Participant).

Impact on applicants

A number of applicants reported that their reason for prioritising particular issues was due to the impact that negotiating the system had on them. This included financial hardship, stress, and health impacts. This reason was given across a number of priority areas.

A key factor in this was the stress associated with waiting to hear the result of an application or waiting for an appeal.

Can't take the stress of not knowing decision for months. Uncertainty. Already ill in pain it is difficult to go on every day with axe hanging over you. Three months waiting for a decision. Need it to end. Can't take the pain and getting thru every day with an axe hanging over me. (Survey Respondent).

The appeals process is traumatic and lengthy. Having someone accompanying me to provide advice and support and being able to speak on my behalf when I was crying would have helped. Being kept up to date about my claim would have been better as I had to phone for an update every week for 7 months before a decision was made. (Survey Respondent).

The stress and anxiety going through the system are unbelievable. If we knew that the system was on our side when we apply it wouldn't be so worrying. The wait to find out the result of claiming drains you - three months is a long time to wait for the outcome. (Survey Respondent).

Other respondents highlighted the impact of going through the application process whilst also coping, or in some cases, coming to terms with a disability, health condition or new diagnosis. Some highlighted that this often coincides with a significant life change or change in personal finances. For

example, when an individual is required to stop work due to their health or caring responsibilities.

Having to deal with a devastating change in your life is stressful on its own, so advice and support are paramount to someone who cannot fully focus on anything else, being kept up to date can help forstall payment of bills etc, while you no longer get a wage and are waiting for a decision, and if doctors/specialists letters were read properly half the appeals would not be needed. (Survey Respondent).

This for me was a very disturbing time of my life. I went from being in a good job I loved to being disabled in a couple of days. The very fact I didn't want this seemed to missed by the people that were there to help. (Survey Respondent).

Whole system improvement

Some respondents suggested that all of the areas listed above should be seen as priorities for improvement within the new system.

I think all of the questions above are applicable... All of the above should really be considered when making any changes to the benefit system as it's like a domino effect, if you make one change it will have a knock on effect with other benefit issues. (Survey Respondent).

It's all important. EVERY stage is important, I actually think ranking them is pointless, from start to finish every person applying needs clarity all the way through. Which one is most important to any person depends totally on which point they are at. EVERY point listed needs to be spot on all the time for every enquiry. If you are asking for general info thats most important to you at that moment...if you feel you need to complain then thats most important then. What matters most is CONSISTENT ACCURATE INFORMATION AT EVERY POINT. (Survey Respondent).

Illness isn't something that is structured and unchanged. It is more fluid and can change drastically in just seconds. New diagnosis, hospital stays, changes in condition should all be much easier to change. (Survey Respondent)

A number of survey respondents and focus group participants highlighted the importance of improving consistency within the system both across individual benefits and across different parts of the country.

Help/advice needs to be consistent across the country, currently there is disparity across geographic regions. (Focus Group Participant)

Chapter 2: What Works Well

Introduction

This chapter considers responses relating to the open-ended survey question “in your experience of the current benefits system, what worked well?” as well as discussions on this topic that took place in focus groups across Scotland. It looks at these responses under the main themes which emerged across respondents. These themes are:

- Financial Support
- Applications
- Assessments
- Advice and Support
- Staff Behaviour
- Timescales
- Receipt of Payments
- Nothing worked well

Key points

Survey respondents and focus group participants highlighted some key things that contributed to a positive experience with the current benefit system.

Friendly, Helpful and Knowledgeable Staff

The most commonly reported factor contributing to good experiences of the current system was where staff were polite and friendly. The manner of DWP staff members and assessors was often noted when participants spoke about having a positive experience. In particular, it was important to respondents when staff showed empathy and understanding. It was also noted when it was clear that staff, particularly assessment staff, had knowledge of their condition.

Benefits Providing Support and Independence

In general, the support offered by benefit payments was recognised by respondents as offering support to live independently and manage their condition.

Simple, Clear and Timely Processes

Where people had felt that the process was straightforward, for example a simple application form, this was viewed as a positive experience. Similarly, respondents spoke of good experiences where things were done quickly.

Flexible Approaches

People also spoke positively when the system met their needs. For example, flexibility around having assessments at home or not at all contributed to positive experiences.

Overall Negative Experiences

It is important to note, however, that a large number of survey respondents and focus group participants were not able to give any examples of where things worked well in their experience. [Chapter 3](#) provides an overview of the main areas of the current benefit system that Experience Panels members felt could be improved.

Financial Support

A number of survey and focus group respondents talked about the support the benefit system gave them and how it had supported them when they needed it. For example, people with experience of disability benefits spoke about times when they were unable to work or when disability benefits helped them to cope with their health condition. This included helping to pay for aides and therapies to help manage their condition and to continue to live a more active lifestyle, for example helping to meet transport costs like taxis, road tax or paying for mobility vehicles.

My MP helped at the Reconsideration stage and my Mobility assessment was increased thus allowing me to retain the mobility car as without this I would have been totally housebound. (Survey Respondent).

Applications

When application processes have worked well, this was when applications were simple to complete. Respondents described a “simple” application as being one that is “clear and specific” or “clear and easy to understand”.

However, some respondents suggested that the simplicity of the application process depends on the benefit that you are applying for. The automatic payments for Winter Fuel Allowance were highlighted by some respondents as a system that worked well. Others highlighted Carers Allowance as an application process which they found simpler to complete.

It was easy to apply for Carers Allowance online, the application was rather straightforward and processed quickly. (Survey Respondent).

A number of respondents highlighted the importance of receiving payments quickly once an application is submitted.

Once awarded benefits all was well, however application and wait for first payment was arduous. (Survey Respondent).

However, some respondents suggested that recently forms have got longer and more complicated.

[My adult son] has a long-term life long condition. He has been on benefits for many years and the application process was straight forward. Recent forms are lengthy and demanding to fill in. (Survey Respondent).

A number of respondents suggested that where forms were longer or more complicated, they required support from a friend, family member, or support service in order to complete the application. This is discussed further in [Chapter 3](#).

The system does not support those that can't do things for themselves. I am the appointee for my son; if he had to complete the PIP application process by himself he would not have claimed it. In fact it took months of persuasion before I could actually apply for him. Consideration needs to be given for people who have severe anxiety, learning disabilities and that find the whole process of claiming benefits too intimidating. (Survey Respondent).

Assessments

A few respondents from both the survey and focus groups described positive experiences of face-to-face assessments for disability benefits. This included some who were not required to go to an assessment, or only were required to attend once.

My disability is a combined hearing loss and sight loss. Both of these aspects can be objectively measured by machines, creating an audiogram for my hearing and a visual field plot for my eyesight. This means that there should be no need for a face-to-face assessment, as the assessment will not yield any extra information. (Survey Respondent).

I am glad to report that my DLA application was processed sensibly on that basis. No face-to-face assessment was required. The correct level of benefit was granted based on the information within my form and the medical data collected from my doctors by the DWP. The entire process, from posting the completed form to receiving the award letter, took place in three weeks flat. (Survey Respondent).

Fortnightly payments, being reassessed on paper without gruelling face to face assessment, being called up by DWP every 6-12 months to find out if anything had changed. (Survey Respondent).

A number of respondents also described having a positive experience during the face-to-face assessment. Factors that contributed to a positive experience included:

- The time and location of the assessment being convenient (for example at home or at a venue local to them).
- The assessment being carried out by someone who was friendly or helpful.
- The assessment being carried out by someone who the respondent felt was knowledgeable about their condition.
- The decision and subsequent payments being made quickly.

Able to detail responses on paper, adding extra information, over a period of time i.e. time to think about response. Able to rearrange face to face interview when unable to make original due to illness. Sympathetic and listening interviewer on day of assessment -was very anxious but she helped me relax. Now awaiting outcome of assessment. (Survey Respondent).

Assessment appointment came quickly. Payments started quite quickly. Nurse who did assessment was experienced and understood my condition. (Survey Respondent).

Advice and Support

A number of respondents highlighted the importance of support and advice services in going through the application and assessment processes. In particular, some respondents expressed concern for how they, their family member, or others in a similar position would have managed to access benefits without the support they received.

I got support from my family when filling out the forms if I didn't have that support I don't know if I would be able to fill it in. I think it should be more easy read for people to understand. (Survey Respondent).

Support from MacMillan cancer financial worker supported me throughout - don't think I would have received anything without her help. (Survey Respondent).

Focus group participants discussed that when information or advice is available, it can be valuable. However, accessing this support can be a challenge.

Had better experiences with help organisations since moving to Scotland. (Focus Group Participant).

Survey respondents described accessing support in applying for benefits from a number of sources. This included friends or family members providing practical support, local authority welfare rights services, and support from

advocacy or third sector organisations. Some respondents had been signposted to support services by the DWP.

The only thing that I found worked well was the support and advice from the Welfare Rights Team and [local] council. Without their advice (and the assistance of a friend) I would probably not have applied or received the benefits I get. (Survey Respondent).

They seemed to take my Consultant's report seriously. I was offered support by the DWP as they categorised me as a vulnerable claimant due to my mental health. (Survey Respondent).

Some felt that certain language or terminology was needed in order to meet the criteria for some benefits, and that support from advice and support agencies was needed to help applicants use the correct language.

The advocates who helped me through the system were incredible. [Third sector support service] helped me with the form. I would not have been able to fill it in using the language and terminology required [in] benefit application forms without their help. This is not because I struggle with describing or understanding things - it is specifically because benefit forms, and the entire system, seem to be set up in such a way that you need to say exactly the right things in exactly the right way to be considered valid. (Survey Respondent).

Staff behaviour

A number of respondents described their experience of interacting with DWP staff members in positive terms. This included describing staff as “helpful”, “kind”, “well-informed”, “reassuring”, “sympathetic”, “polite”, “efficient”, “pleasant”, “understanding”, “caring”, “patient” and “compassionate”.

I found what has worked well was the staff I have spoke with on the phone have been very helpful and took the time to understand and listen to me and they have also taken the time to help me understand things. I also had a person out to the house to help sort some paper work out and he was also very helpful and if I didn't understand something he was able to explain it in a way I understood it. (Survey Respondent).

Respondents described the positive impact that a helpful member of staff can make on their ability to navigate the application process, and noted that this can vary depending on the call centre employee.

Had positive experience when applying for Scottish Welfare Fund – very active and helpful phone line staff. Noted that it varied depending on which call centre employee you talked to. (Focus Group Participant).

Some respondents described staff signposting them towards other services or benefits.

The discretionary payment was small, but I was delighted to hear that the Scottish Government was offering this. Again a massive help and was recommended to me by a member of staff. I was also directed to the Social Welfare Fund who helped me through an extremely difficult time. (Survey Respondent).

A number of respondents highlighted the importance of staff having good knowledge or understanding of how a disability or health condition might affect an applicant.

The assessor who came to assess my son for his PIP understood his condition and helped him through the assessment by her attitude - she stood out amongst everyone else I have had to deal with. (Survey Respondent).

However, there were a number of respondents who described less positive experiences of interacting with staff members, including staff being unhelpful, uninformed or rude. This will be discussed further in Chapter 3.

Being able to communicate face to face with a person who actually wanted to help me was a welcome bonus. (Survey Respondent).

Timescales

A few respondents described positive experiences where applications, assessments and payments were processed quickly and efficiently. This included, for example, sending out application forms quickly. However, many described the process as taking a long time. The challenges with timescales will be discussed further in [Chapter 3](#).

When the decision to award was finally made things moved quickly, it just took a long time to get there (Survey Respondent).

Receipt of payments

Some respondents described the receipt of payments as something that works well in the current system, including that payments are made on time.

Benefits seemed to be paid on time correctly overall quite fair and accurate (Survey Respondent).

Others commented that regular payments, being made on time, are important in allowing recipients to budget. Flexibility in how regularly payments could be made was also highlighted as an advantage to some respondents.

Some respondents also commented that it works well that payments are backdated to the date of application, or to include periods where recipients weren't paid. Others commented that once their award had been confirmed the payment was made quickly.

The application process was easy and money was backdated to when I became a carer. (Survey Respondent).

Respondents who felt there were no elements that worked well

However, alongside these positive comments a large number of respondents commented that there was “nothing” that worked well in their experience of the current social security system or described only negative experiences in response to this question. Many of those respondents raised systematic issues around the application and award process, delays in application processes, and cultural issues around how service users are treated by the system or staff. This will be discussed at length in [Chapter 3](#).

Nothing works well with the current system it is long winded unsympathetic and almost an us against them type culture. (Survey Respondent).

Nothing works well, time delays and barriers are there at all points. (Survey Respondent).

A number of respondents also commented on barriers they faced within the system, including lengthy and complicated processes, challenges getting through on the phone and finding the process stressful or emotionally difficult.

Some respondents described failures in the system including paperwork getting lost and incorrect information being provided. In particular, a number of respondents spoke about the PIP application and assessment process as being a poor experience, including describing it as “humiliating” and “degrading”.

Nothing it's shambolic - left hand does know what right hand is up too. PIP assessment is a joke. (Survey Respondent).

Chapter 3: What Could Be Improved

Introduction

The survey asked respondents two main questions around improvements:

- “In your experience of the current benefit system, what could be improved? “
- “Tell us about any obstacles or barriers you faced in accessing the current benefit system.”

In focus groups, participants were asked to consider the top 3 things that the Scottish Government should improve about the benefit system. As a result, the discussion largely focused on their difficult experiences of parts of the current system. This chapter will provide an overview of aspects that panel members felt could be improved in the current benefit system.

Key themes

In the survey and focus groups panel members spoke at length about difficult experiences when navigating the current benefit system. Some overarching themes became clear when analysing this data.

Inflexibility of the Current System

Respondents often spoke about experiences that highlighted inflexibility in the current system. This included no choice in how application forms are completed or communication channels. This is particularly difficult for those with mental health conditions or conditions that make certain types of communication impossible. Practical barriers also included expected travel to assessment centres, short notice for attending assessments or tribunals and unwillingness to meet care or support needs for people with disabilities. Some also described how services were unable to tailor their systems to meet different additional support needs.

Lack of Transparency

Respondents also spoke about issues that arose from a lack of transparency in the system. A lack of clear information on what to expect from processes and long wait times without information often led to feelings of powerlessness when navigating a difficult process. In the context of a lack of information, respondents often spoke about finding out about the system from informal

networks and the experiences of others. Often this increased anxiety around interacting with the system.

Lack of Trust

A strong theme emerged around distrust in the relationship between the DWP and service users. Participants often spoke about a distrust of the DWP and the benefits system, but also that they felt distrusted by DWP staff. Participants spoke regularly about feeling like they were 'on trial' and that the presumption was that they were claiming benefits fraudulently.

Impact on Users

The impact that interacting with the system had on people was clear in the responses to the survey and focus groups. On the whole, the process of applying for benefits was often a source of stress and anxiety and participants feared having to go through the process again.

General statements about the whole system

A number of respondents made broad statements, suggesting that the system as a whole needs to be improved.

The full benefits system needs a major revamp (Survey Respondent).

Application Forms

Length and Repetition

Many respondents highlighted application forms as being an important area for improvement. In particular, the application form for Personal Independence Payment (PIP) was regularly discussed by respondents as a particularly challenging part of their experience.

A particular issue raised was the length of the form. Some respondents described the application form as being too long or repetitive. This makes the forms difficult for applicants to complete, especially within the required timescales. Respondents highlighted that the length of the form can place a burden on carers or support agencies who provide help to complete the application.

The PIP application is very long and can be confusing. (Survey Respondent)

Respondents also spoke about the forms being repetitive, asking for the same information in different ways.

They are very repetitive so you keep telling them the same things in different ways. (Survey Respondent).

A number of respondents felt that this was deliberately trying to trip applicants up, put people off of applying, or that the system assumes applicants to be fraudulent.

Explaining Conditions

Respondents spoke about the difficulties when trying to explain their condition in the PIP form, noting that the questions were not always relevant or appropriate to their specific medical condition. In particular, panel members spoke about difficulties in explaining 'hidden' and 'fluctuating' conditions or mental health conditions.

Long phone calls & forms. If you do not fit into the set categories or your disability is hidden, you miss out on help. Perhaps things could be simplified and claimants not automatically assumed to be lying if a disability is not obvious. (Survey Respondent).

Including Supporting Evidence

A number of respondents suggested that medical evidence provided by the applicant's GP or specialist should be regarded as sufficient for a PIP application and not require duplication in forms or assessments.

Shorter forms. Medical evidence should be enough and not disregarded. Assessment more often based on application alone when there's proof. There shouldn't be any tricks or traps. (Survey Respondent).

Application forms that require a list of medical examinations, Consultant and GP visits. Information that is readily available from the GP. Why is the applicant instructed to find and collate this information. Another repetition whose sole purpose appears to be in place to 'trip up' and cause stress to the applicant and, where necessary, the person acting on behalf of the applicant. (Survey Respondent).

This duplication and breakdown of trust was highlighted as an area which could be improved in the new social security system. Some also highlighted accessing the forms in the first place to be an area for improvement.

Simplified forms - not as longwinded or duplication of data. More opportunity to let the person write how their disability etc. affects them not how the pre-determined issues are managed. Easier access to forms - download or just pick up in jobcentre (without pre form telephone calls/meetings etc.). (Survey Respondent).

Inflexibility of a Paper Form

Respondents spoke about the inflexibility of the current PIP form and that paper forms can be particularly difficult for some claimants. A number of respondents noted that filling in forms by hand can be difficult or exacerbate their condition, and that for them, online forms would be better. Others highlighted that online or phone based application processes do not meet everyone's needs, and that paper based, or face-to-face services may be more accessible for some people.

As my MS progresses, I find writing and typing increasingly difficult. The thought of having to fill out a PIP form yet again next year fills me with dread. (Survey Respondent).

PIP applications forms - should be able to fill online as it took me days to complete due to having to write everything which caused pain and discomfort. They are also a nightmare to complete as you often have to repeat what you have already stated. Length of time for processing is way too long. (Survey Respondent).

Language on Form

The language used in the forms was discussed as a barrier to accessing the system. Some respondents suggested that the language used in forms could be simpler or easier to understand, in “clear English”, as well as clear what information is needed. Others highlighted the tone of language as being important in reducing the stigma and stress associated with applying for benefits.

On the majority of claim forms, the wording of the questions are confusing or lean towards being biased against the claimant or the questions give little scope to fully explain how a situation affects you. (Survey Respondent).

The forms should be CLEAR in WHAT information they need, and not designed to deliberately mislead an applicant from providing relevant information. The boxes should be a decent size so as not to discourage people providing a decent amount of information that allows the best possible representation of the applicant’s situation and difficulties. (Survey Respondent).

Timescales

The tight timescales to return forms was raised as a current issue. Respondents described the need for a longer time period for returning application forms. This was important due to delays in postage, when the application requires supporting evidence or when the individual requires support (e.g. from Citizen’s Advice) to complete the form.

Give us longer to fill out forms. 4 weeks (including posting both ways) is far too short. It can take me 3 weeks just to get a GP appointment. (Survey Respondent).

Application and/or benefit update forms that are post dated arriving 8-10 days beyond that date. Which means the form completion time is reduced by up to 7 working days. It appears this practice is undertaken to apply unnecessary pressure and/or stress on the applicant. Why? (Survey Respondent).

Life-long and Degenerative Conditions

Some respondents suggested that those with degenerative or life-long conditions should not be required to go through the process of applying for PIP again and again. Instead, some suggested that this might be done through simply updating their information or submitting new medical evidence as their condition changes or progresses.

People who need to reapply for benefits should not have to refill out new forms. This information should already be held on a central database. Claimants should only have to provide updated evidence (savings/medical sick note etc.). (Survey Respondent).

Face to Face Assessments

The functional assessment for Personal Independence Payment was discussed by a large number of respondents as a key area requiring improvement.

Wait Times

A number of respondents highlighted difficulties caused by the time between submitting an application and the date of assessment as being an area of improvement. This wait was described as “far too long”, and “unacceptable”, with one respondent describing a six month wait to get an assessment appointment. Some described also having to wait for the decision to be made after their assessment, further delaying payments.

Repeat Assessments

It was also highlighted that repeat or unnecessary assessments could be distressing, and that assessments should not be required for people with a lifelong or degenerative condition. Some respondents also suggested that medical evidence provided by the applicant’s GP or specialist should be, in many cases, sufficient with no additional assessment required.

Accessibility of Assessments

Respondents described a number of challenges faced in attending face-to-face assessments for Personal Independence Payment. This included the accessibility of buildings, and the location of the assessment both in terms of

distance and transport links. Some also described being too unwell to attend an assessment, or finding the experience stressful or upsetting.

Getting to the appointment was very difficult and when I have to go for my next one, I will struggle as I don't have a car and getting to the assessment centre by public transport from where I stay is not easy. (Survey Respondent).

If unable to attend an assessment (due to distance, unavailability, illness, etc.) this should not be classed as a refusal to attend. (Survey Respondent).

The door of the assessment centre is heavy and difficult to open - I had to use my shoulder to push it open going in and then struggled pulling it open to leave. Both caused me pain. There was a room available for assessment on the ground floor opposite waiting room but instead they made me walk all the way back to reception area and get a lift (which had no seat) and then another long walk to the room. I ended up in bed for two days following this assessment due to pain and exhaustion. (Survey Respondent)

Respondents also spoke about people who are at assessments to support them not being allowed to speak or provide information. This was said to be particularly difficult when supporting someone who has a condition like autism, or one that affects memory or speech, as they may not be able to give an accurate assessment of their own needs and/or could find it distressing.

[My daughter] was very distressed and upset when she was told that she could not have her mum with her as the ATOS Assessor said that she had to be assessed on her own. (Focus Group Participant).

Knowledgeable Assessors

Respondents emphasised the importance of having assessors who have relevant knowledge and training to enable them to make an informed assessment of their capabilities and needs.

Assessments should be carried out by an assessor who is fully conversant with the conditions of the claimant. My assessment was carried out by someone who didn't understand my condition, her physical testing was totally inadequate nor did it take into account the fluctuations in my health (Survey Respondent).

3 weeks of training does not make a competent assessor. (Survey Respondent).

Some respondents described feeling that the assessment was not appropriate to their health condition. This included the type of questions asked, as well as respondents saying they were asked to do activities that caused pain or exacerbated their condition.

Particular areas for improvement included assessments for people with fluctuating conditions and for people with multiple health conditions. A number of respondents also felt that their assessment did not take into account their mental health.

The medical assessment in my eyes is not as it implies medical and does not fulfil all medical needs. The way the data is collected is not centred and not personal, many things that are important are missed out like the amount of pain endured. (Survey Respondent).

The assessment was extremely uncomfortable and was made to do physical things that caused pain. I refused to do one as had been specifically told by my physio not to do that movement as it could cause major problems. (Survey Respondent).

Behaviour of Assessment Staff

Respondents commented that the behaviour of staff involved in the assessment was an area that could be improved. Respondents spoke of a distrust of the assessors, commenting that it felt like “I was on trial” or “they were trying to catch me out”. Others described staff as “rude” and felt that staff behaviour negatively impacted on them or the outcome of the assessment.

The assessor was rude and imperious, and actually had the gall to shush me when I was trying to offer my mum some words of support. She then went on to question the medications that'd been prescribed by doctors *specialising* in pain medicine. (Survey Respondent).

During my first assessment I asked my assessor what she had written and she refused to tell me. This made me very distressed and I became very ill worrying about this for months afterwards as I could not stop worrying about what she had written about me and why she wouldn't let me see it. At my second assessment I had an advocacy worker present and she made sure that the assessor treated me properly and spoke to me slowly and clearly. She also explained to the assessor how important it was that I knew what was being written about me and had the assessor tell me everything that she was writing. It was a completely different experience. (Survey Respondent).

The Need for Assessments

Some applicants emphasised that disability benefit assessments should only be carried out when necessary, and that evidence provided by medical professionals should be enough. Respondents were concerned that assessments do not always capture pertinent information about the applicant's capabilities or needs.

Everything should come from one application and one assessment (if necessary). Doctors statements should be enough, patients shouldn't need to justify their condition(s). (Survey Respondent).

Assessment - this is not fit for purpose (a snapshot of a person's care/mobility needs does not reflect how a person is over a year; the assessor's observations are personal and not reflective of the person - the person may look ok, but does not reflect the amount of help required to look 'presentable'. As the assessor has never met the person before, how can they comment on their physical appearance and their actions). (Survey Respondent).

Distrust of the Assessment Process

Some respondents felt that their experience of face-to-face disability benefit assessment was unfair, inaccurate, or biased. This included a number who felt that their assessment report included false information. Similarly, some respondents questioned the motivations of private companies who are involved in the assessment process, suggesting that they were motivated by targets or cost saving, rather than the needs of the individual. Some felt that assessments should be routinely recorded to stop inaccurate reports being submitted.

Get ATOS out of the assessments. They're horrible and just don't make fair assessments. (Survey Respondent).

The assessments should not be incentivised, or completed by a third party company. It should be a professional in that particular field who conducts the assessments. (Survey Respondent).

A number of respondents also described being observed by staff outwith what they considered to be the formal assessment and that this made them feel like they were not trusted or that the assessor was trying to catch them out.

By the end of it all, my mum was in tears of stress and agony. And just to put the cherry on top, we noticed as we were going out towards the taxi that one of the staff was watching us from the window. The whole thing felt like we were under the eyes of the damn Inquisition. (Survey Respondent).

Appeal process

Many respondents highlighted the appeals process as a key area for improvement.

Stress Associated with Appeals

A number of respondents commented that they were unable to appeal due to the stress associated with this process, and therefore accepted what they felt was an unfair or inaccurate decision.

I know their decision is wrong, but do not have the time nor capacity to fight this further - I need to spend all my time / energy caring for her. The appeal stage beyond mandatory reconsideration is too complex and stressful and I feared losing what I already had. (Survey Respondent).

[The] appeal system is awful and when you have mental health issues it is so hard to explain. When you lose appeal you feel as if you are scum and a liar. (Survey Respondent)

Some respondents felt that appeals system is unsympathetic and does not understand the way that health conditions can affect different people in different ways. A number of respondents found the process very stressful, with some suggesting that it can make people “suicidal”.

The DWP and ATOS and also the Courts and Tribunal service, all make assumptions and don't fully understand the way in which medical conditions affect people in "reality" it's a box ticking exercise, black or white, yes or no, medical conditions, disabilities and long term illness cannot be pigeon boxed, they are unique to that individual and people deserve to be assessed with this in mind. (Survey Respondent)

My wife was not allowed to help me or speak in my tribunal because I had a representative there [advice service]. Unfortunately my representative didn't help me in any way nor stand up for me in the tribunal and, due to my condition, I became unable to answer questions and it became a very traumatic experience. I remain very upset about this two years later. I felt that the tribunal was boringly repetitive for my representative and the panel members and that the panellists were finding it difficult to both see me, and treat me, as another human being rather than just another pathetic, possibly disabled, person to judge and get through. (Survey Respondent).

Discouragement from Appealing

Others felt that either the staff or the system deliberately discourage people from appealing a decision.

The two women I spoke to (one was a senior manager) both actively tried to deter me from challenging the award. I was on the phone for nearly 40 minutes whilst they argued with me. In the end the manager conceded that a reconsideration was permissible. (Survey Respondent).

The issue of applicants feeling unable or discouraged from appealing decisions may be exacerbated by the short time period which applicants have to lodge an appeal against their benefit decision.

In this respect if there is to be an appeal system, it is necessary, in my opinion, to allow a greater length of time for the disabled person to organise their appeal and the support needed to attend hearings. (Survey Respondent).

Percieved Consequences of Appealling

Some respondents raised the concern that appealing a decision can put their benefit at risk of being cut or stopped all together. This was particularly a concern relating to taking a case to tribunal, where respondents reported that they had been warned against taking this step by staff, judges, or outside agencies on the basis that their existing benefits could be stopped.

My father now needs more care than the standard AA but we have been told there is a risk if we appeal for the higher rate we could lose the standard rate. (Survey Respondent).

The judge at the tribunal 'warned' me that they had some info that could result in me losing the entire award including the 'care' element but would only tell me what that was if I went ahead of the Tribunal and risked everything if I couldn't, without any prior warning, explain or show evidence to the contrary. (Survey Respondent).

Mandatory Reconsideration

A number of respondents expressed a degree of distrust in the rigour and fairness of the mandatory reconsideration process. 'Mandatory reconsideration' is the first step in challenging a decision, acting as an internal review of the decision. Some respondents and focus group participants felt that staff were unlikely to disagree with their colleague's assessments, and saw this as an unnecessary step that adds to the length and stress of the appeal process overall.

A mandatory reconsideration where there is little or no prospect of success but rather a tick box exercise which can often delay an appeal. (Survey Respondent).

I think the mandatory reconsideration period should be done away with; it just adds time and stress on to people and leaves them without money for longer. (Survey Respondent).

Then if the decision is no to have to go through mandatory reconsideration is simply a stalling exercise because they will mostly uphold the decision of a colleague and will find every ridiculous reason to do so. (Survey Respondent).

Transparency of Appeals Process

A number of respondents described a lack of transparency in the appeals process. This included not having access to information and evidence relating to their case, or feeling that the system is biased or deliberately difficult to navigate.

I have asked for a statement of facts from the tribunal as to why I am not getting the mobility. I have been waiting for almost 2 months for the response. (Survey Respondent).

In my opinion and experience the current system sets claimants up to fail at every stage, having had to take my husband's previous claim to tribunal, I am of the opinion that under the current system, unless one is tenacious enough to keep fighting, and it is a fight, then you will be denied PIP. (Survey Respondent).

Wait Times for Appeals

Respondents described long waiting times for going to appeal, which can be particularly problematic when benefit payments are stopped in the interim period.

Then there is an extremely long wait for a decision, and when you read it you feel as if they haven't listened to a word you said! Then another wait for an appeal process. Very disheartening, and depressing. Making you feel worthless and that you are actually begging for something you're not entitled to. (Survey Respondent).

I just had to go to Tribunal while trying to claim PIP because I missed an appointment due to my disability. This was stressful and entirely unnecessary. They wouldn't accept I had good reason to miss the appointment even though my support worker called several times to explain. Meanwhile they have stopped my Disability Living Allowance. (Survey Respondent).

Communications and Language

Survey respondents and focus group participants highlighted areas for improvement around the communications about benefits, including inflexibility within the system.

Letters

Postal correspondence with the DWP was frequently discussed as an area for improvement. This related to correspondence sent to the DWP not being acknowledged or responded to. Respondents also raised issues with letters received from DWP. The main issues with letters from the DWP tended to be around clarity of wording, accuracy and tone.

The wording of letters could be better. I get letters starting with "due to a change to your circumstances" when to my knowledge there have been none. [I have got] letters months after deductions have been [...] to my housing costs [...] that put me in arrears through no fault of my own. (Survey respondent).

The letters are threatening, especially if people have mental health issues. The language of the letters requires to be changed. There is inconsistency of communication as sometimes the Contact Centre staff are OK and sometimes they are very abrupt and rude. (Focus Group Participant).

Phoning DWP

Respondents spoke about the length of time required to make phonecalls to the DWP, both in terms of long wait times and being passed from person to person. Some respondents spoke specifically about challenges and frustrations with the initial PIP telephone call. Also mentioned was the behaviour of staff working in call centres.

The help lines are a joke, hanging on the phone for up to an hour to speak to someone. I gave up trying to apply for myself. (Survey Respondent).

We need to record the calls as their behaviour is bullying. If you make a complaint, you feel that you will be targeted and you feel worthless. (Focus Group Respondent).

Inflexibility in how customers were communicated with was raised by some survey respondents and focus group participants. For example, a few respondents spoke about the phone being a particular barrier because of their condition.

I have huge issues around telephones. Having autism means it's difficult/almost impossible for me to communicate by phone. I get extremely anxious and I find it difficult in terms of knowing when it's my turn to speak and understanding inference, if I can't see a person's face. (Survey Respondent).

In bed with depression after months awaiting claim outcome, completely draining. Then received phone call from DWP to say I had been found fit for work. This was not the right method for me, at least a letter allows people with mental health issues the choice to delay dealing with it if needed. (Survey Respondent).

A couple of respondents mentioned specifically the DWP 'on hold' information on the call line. This was felt to be threatening or off-putting. Others mentioned the hold music as being particularly off-putting.

The horrific Vivaldi music is painful to listen to when trying to call and speak to someone. (Survey Respondent).

Costs Associated with Applying for Benefits

Respondents spoke about multiple costs associated with applying for benefits. Several respondents noted this as a key barrier to accessing the system, particularly when on low incomes and/or in poor health. This included

call costs when phoning the DWP, especially when subjected to long wait times or when calling from a mobile.

Cost of mobile calls to DWP one of ours cost £18.00. (Survey Respondent).

The cost of phoning the DWP if you only have a mobile is outrageous. I moved house, so sent a letter informing them of the change of address rather than pay for a ridiculously expensive phone call. My next set of payments weren't made. I then rang up to be told I had been sanctioned for sending in a letter, rather than phoning, to report a change of circumstances. "you should have read the rules", he said. (Survey Respondent).

Some PIP applicants also spoke about costs associated to gather supporting evidence for application or appeal, for example letters from doctors or legal advice.

I had to pay for a doctor's letter at MR (mandatory reconsideration) stage to get it. It should be up to the DWP to get all relevant info. (Survey Respondent).

A few respondents also spoke about the costs associated with attending face-to-face assessments, for example, having to travel at peak times or by taxi to make appointments.

Some respondents also spoke about costs that they incurred that were associated with their distrust of the DWP. For example, photocopying large amounts of paperwork to keep a copy and sending correspondence by recorded delivery.

An astounding amount of mail sent to the DWP seems to go missing. I send every thing by recorded delivery and copy everything beforehand. (Survey Respondent).

Some respondents also felt the need to subscribe to online information and advice sources to complete claim forms. A recurring example was the 'Benefits and Work' website which costs £19.95 per year.

Information, Advice and Support

Respondents spoke about a lack of clear and accessible information and advice on what they are entitled to, particularly related benefits that people may be entitled to. Likewise, in focus groups, participants often spoke about the difficulty in finding out about benefits in the first place. Routes into the system tended to vary, however, people were often told about benefits through their informal networks.

There is very little information outside the job centre and the citizen's advice centre. The information should be much more easily accessed. (Survey Respondent).

Assistance to complete and advice on what to claim for would be helpful. For example, we were unaware my father was entitled to attendance allowance until a nurse informed him. He was lucky to have assistance to fill in the form through help at the Maggie's Centre. I know he would not have done this without help. I think that if someone makes a claim they should be informed of all benefits they may be entitled to claim for. (Survey Respondent).

Finding out what I was entitled to. This only became clear after visiting my council run advice team. I am very computer literate, but even I have found the online info hard to dig out! (Survey Respondent).

Respondents highlighted the importance of independent advice and support, particularly when navigating a complex system. A number of respondents raised concern about the capacity of support agencies to meet the demand, especially within tight timescales.

P.I.P form is nearly 40 pages and very complicated. I was able to get help from somebody from Citizens Advice. Without their help I wouldn't have been able to apply successfully. (Survey Respondent).

The process of applying or reapplying for benefits has been so complicated that I - and countless others - have had to accept help from third parties (such as Citizens Advice) just to complete the paperwork. (Survey Respondent).

Getting an appointment with a support worker and getting the firm back in time can be difficult. (Survey Respondent).

Impact on service users

A common theme that emerged throughout the survey responses, and in focus groups, was the impact that the system had on users. In particular, respondents often spoke about feelings of stress and anxiety. This was often caused by:

- short timescales to gather information and submit claims.
- difficult parts of the process, as discussed above.
- long and uncertain waiting times for responses.
- difficult encounters with staff, particularly in relation to assessments.
- stigma associated with claiming benefits.

I spend from the time I write any form to the time I get the response on my knees mentally with fear, anxiety and stress. (Survey Respondent).

Respondents also spoke about feelings of fear. Some spoke generally about a fear of 'losing everything' if their claim was not accepted. Others spoke more specifically about specific triggers, for example, about fear and anxiety experienced when a 'brown envelope' is received from DWP or fear of going through the process again. Fear was sometimes given as a reason for not updating information or appealing decision.

If a brown envelope arrives I have cried before being able to open it as I know the clock starts ticking. It has so far only been standard letters but I've been through that anxiety each time. (Survey Respondent).

Some respondents spoke about the impact that going through the system had on their conditions. This included aspects of the process itself (e.g. written forms or face-to-face assessments) causing pain or interacting with the system exacerbating mental illness.

I was assessed again ... where I was made to walk back and forth from various rooms while using my walking stick which left me in great pain... (Survey Respondent).

Nothing at all worked well, the whole system caused more stress and caused my illness to worsen, going through the process was agony especially as I was trying to come to terms with this devastating illness. (Survey Respondent).

Suffering with depression and anxiety and being made to jump through hoops made me 100 times worse. After losing my car I was secluded from everyday life and people which made it difficult to be around other people again after I won my appeal and motability car again. (Survey Respondent).

Annex A – Methodology

The Survey

The 'About Your Benefits and You' survey was carried out between July and September 2017. The survey was multi mode with panel members being able to complete the survey online, in hard copy or over the phone. This included offering respondents a choice of language to complete in and a range of other accessible formats. The survey was for adults, over the age of 16.

The experience panels are longitudinal so information from the 'About Your Benefits and You' survey was added to information collected during the registration phase 'Have Your Say', including postcode, accessibility requirements and information about the benefits that respondents have experience of.

'About Your Benefits and You' asked respondents about their present and past experience of applying for, getting, challenging and appealing:

- Disability Living Allowance (DLA)
- Personal Independence Payments (PIP)
- Attendance Allowance (AA)
- Severe Disablement Allowance (SDA)
- Industrial Injuries Disablement Benefit (IIDB)
- Carer's Allowance (CA)
- Funeral Expenses Payments (FEP)
- Sure Start Maternity Grants (SSMG)
- Cold Weather Payments (CWP)
- Winter Fuel Payments (WFP)
- Discretionary Housing Payments (DHP)
- Scottish Welfare Fund (SWF)
- Universal Credit (UC)

Respondents answered both in relation to their experience of applying themselves, and their experience of helping others. Responses also included reference to wider benefits, for example ESA, and this is noted where applicable in the text. Respondents were asked to rate their overall experience from 'very good' to 'very poor', and were asked to provide their top three priorities for Scottish Government to improve in the new social security system. They were also asked a series of qualitative questions relating to their experience which are analysed in this report.

Respondents were also asked basic demographic information about their age, gender, disabilities and long term health conditions, caring responsibilities, and the make-up of their household.

Following data cleaning, 1,144 experience panel members completed the 'About You and Your Benefits' survey.

Analysis of the quantitative data (from the tick box questions), including a breakdown of respondents, was published in November 2017 and is available at: <http://www.gov.scot/socialsecurity-experiencepanels-aboutyou>.

The focus groups

35 focus groups were held in locations across Scotland, meeting with more than 250 panel members. These focus groups were structured around a discussion of respondent's priorities for improvement in the new social security system and their reasons for this.

Analysis and reporting

The combined dataset from the survey and focus groups is reported here after analysis by Scottish Government researchers. Survey and focus group respondents were asked about their experience of the current benefits system in general, rather than in relation to their experience of specific benefits. This analysis is therefore based on key themes relating to the system generally, and draws out detail relating to individual benefits where responses explicitly mentioned a specific benefit.

This data was analysed using NVivo 11 software. For each open-end question 10 per cent of responses were manually coded in full to identify reoccurring themes. Automated coding and analysis tools, including word frequency analysis, coding query and text search tools, were then used to support the analysis of the full dataset. The same approach was taken to analysing the focus group reports.

This approach to analysis allowed researchers to identify key themes relating to priorities for the Scottish Government to consider in the new system, what currently works well and areas for improvement. The report has used a large number of quotes from respondents and focus group participants to illustrate themes that were identified through this analysis. Evident spelling mistakes and typos have been corrected in this report, but use of colloquial language and expressions such as use of capital letters for emphasis has been kept.



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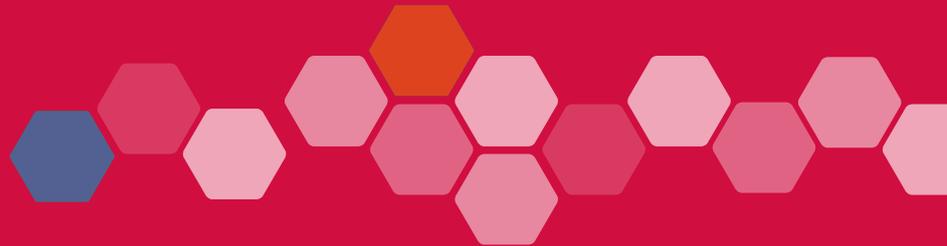
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