Health and Social Care Alliance Scotland (the ALLIANCE)

A new social security assessment process for Scotland: the views of seldom heard people

Research report

June 2017

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

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Introduction

As part of its national consultation on the devolution of social security powers, the Scottish Government commissioned the Health and Social Care Alliance Scotland (the ALLIANCE) to consult seldom heard people in Scotland on what a new Scottish social security assessment process should look like.

From January to March 2017 the ALLIANCE carried out a rapid, small-scale, mixed methods consultation project. The target audience was people with direct experience of social security – in particular the entitlements that are being devolved – who identify as belonging to one or more seldom heard group, including:

- People living in rural or remote Scotland
- Members of the LGBT+ community
- People with experience of homelessness
- Members of the refugee/asylum seeking community
- People with lived experience of mental health issues
- People living with sensory impairment/ multiple conditions
- Members of the BME community
- People with learning difficulties
- Unpaid carers
- People aged 65+

This report sets out the findings from a national stakeholder round table event, an online survey of 238 self-selecting respondents and 14 focus groups comprising 97 participants.

Acknowledgements

The ALLIANCE would like to thank all the people who shared their views with us and the members and partners that supported this project.

About the project

Aims and objectives

Responsibility for several social security entitlements, including disability and carer entitlements, is being devolved to Scotland[1]. From July to October 2016, the Scottish Government carried out a national consultation to inform the content of a new Scottish Social Security Bill[2] that received over 500 written responses[3].

In December 2016, the Scottish Government commissioned the ALLIANCE to specifically consult seldom heard people around Scotland on what a new social security assessment process should look like.

Exploring this question directly with seldom heard people who navigate the current system was intended to support a future social security system designed to reflect the values of person centeredness, co-production and human rights and help fulfil the Scottish Government's Vision[4] and Principles[5] to treat people with dignity and respect.

The project objectives were to:

- Engage with representatives of seldom heard groups who access the social security system and Third Sector agencies that support/work with them to support the co-design of a new social security assessment process.
- Convene up to 12 engagement events with seldom heard groups who use the social security system.
- Carry out an online survey aimed at people from seldom heard groups and promoted by ALLIANCE members working with them.
- Identify a core group of people representing seldom heard groups that can provide ongoing guidance to the social security development process.
- Establish what different seldom heard groups would recommend for a future social security assessment process, including, for example, access to support for claimants; access to advice and independent advocacy; and best communication methods (e.g. face-to-face; online; telephone).
- Report on the engagement activity and produce recommendations for a social security assessment process that reflects the culture and values of person centeredness, co-production and human rights.

Design

The project was designed to address the core question: "What does the new Scottish Social Security Agency need to know in order to design the best possible social security assessment process?"

> *What does the new Scottish Social Security Agency need to know in order to design the best possible social security assessment process?*

The project started with a national round table of key stakeholders that self-identify as seldom heard or work for/with seldom heard groups. Round table participants helped to identify some of the major issues facing seldom heard people in the current social security system and shared views about what a new system could look like. They also provided input and advice to project design, helped publicise the online survey, and worked in partnership with the ALLIANCE to deliver focus groups.

The national round table event was followed by an online survey consisting of 11 questions that ran for 8 weeks from 23 January to 19 March 2017 (see Appendix A). Mandatory questions were designed to ensure the survey gathered the views of the target audience – people with direct

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[1] http://www.gov.scot/Topics/People/fairerscotland/Social-Security [2] http://www.gov.scot/Topics/People/fairerscotland/Social-Security/Consultation
[3] http://www.gov.scot/Resource/0051/00514351.pdf [4] http://www.gov.scot/Topics/People/fairerscotland/future-powers/Publications/Future
[5] http://www.gov.scot/Topics/archive/future-powers/future-powers

experience of social security who self-identify as seldom heard. The survey was widely publicised using the ALLIANCE’s social media platforms, via our members, key stakeholders and Third Sector partners.

With the support of ALLIANCE members and partners, the project also organised 14 focus groups with 97 seldom heard people around Scotland over a four week period from 16 February to 18 March 2017. The focus groups used a facilitator discussion guide, note-taker guidance and template and participant information sheet and consent form, all of which can be found at Appendices B-D.

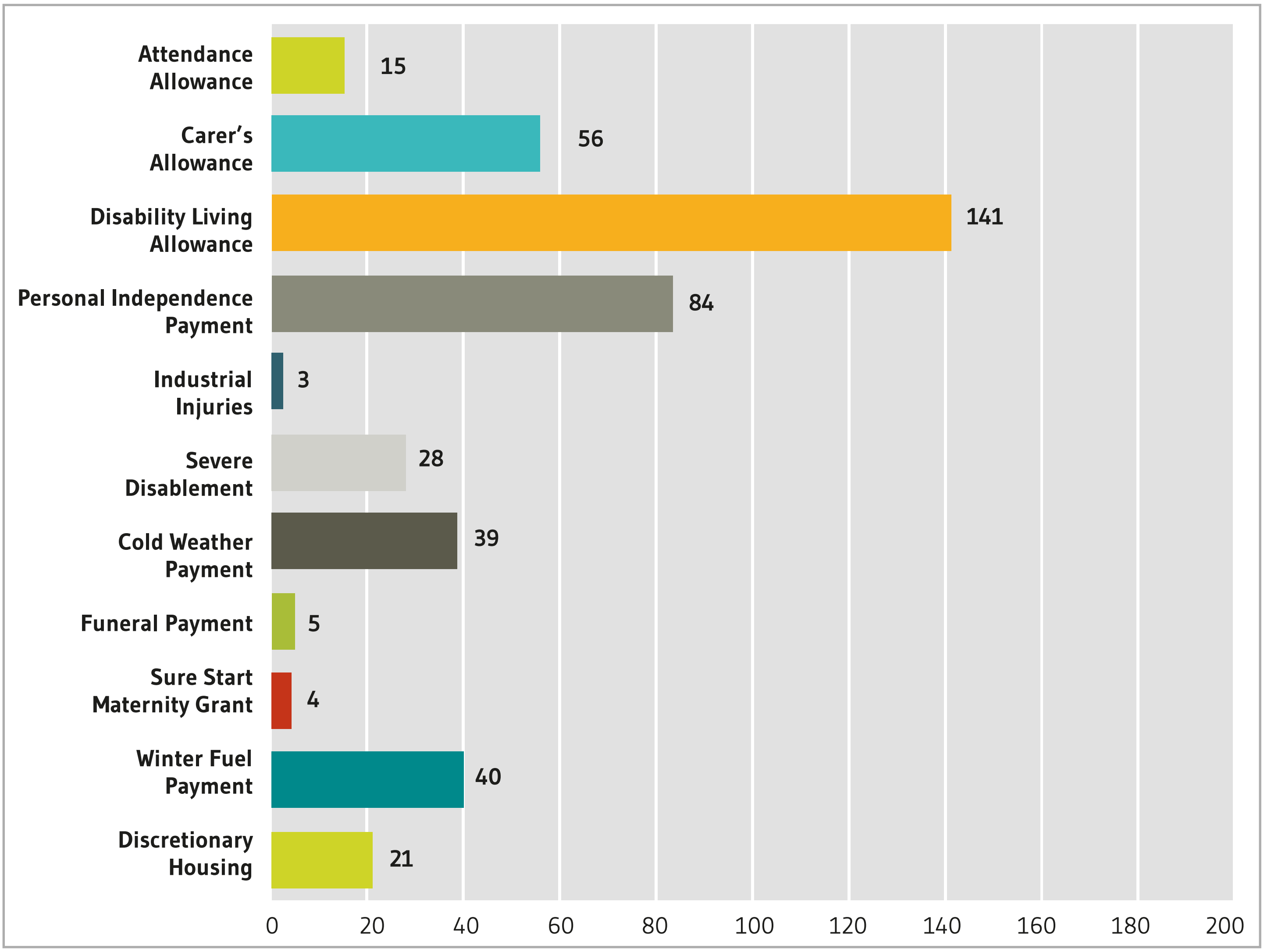
Who took part?

Online survey respondents

238 self-selecting individuals with direct experience of social security who identified as belonging to one or more seldom heard group completed the online survey.

Experience of social security

The survey asked respondents to indicate which social security entitlements they had accessed or applied for. Given that many people are in receipt of more than one, the question was multiple-choice. It was also mandatory to ensure that respondents had direct experience of at least one entitlement being devolved.

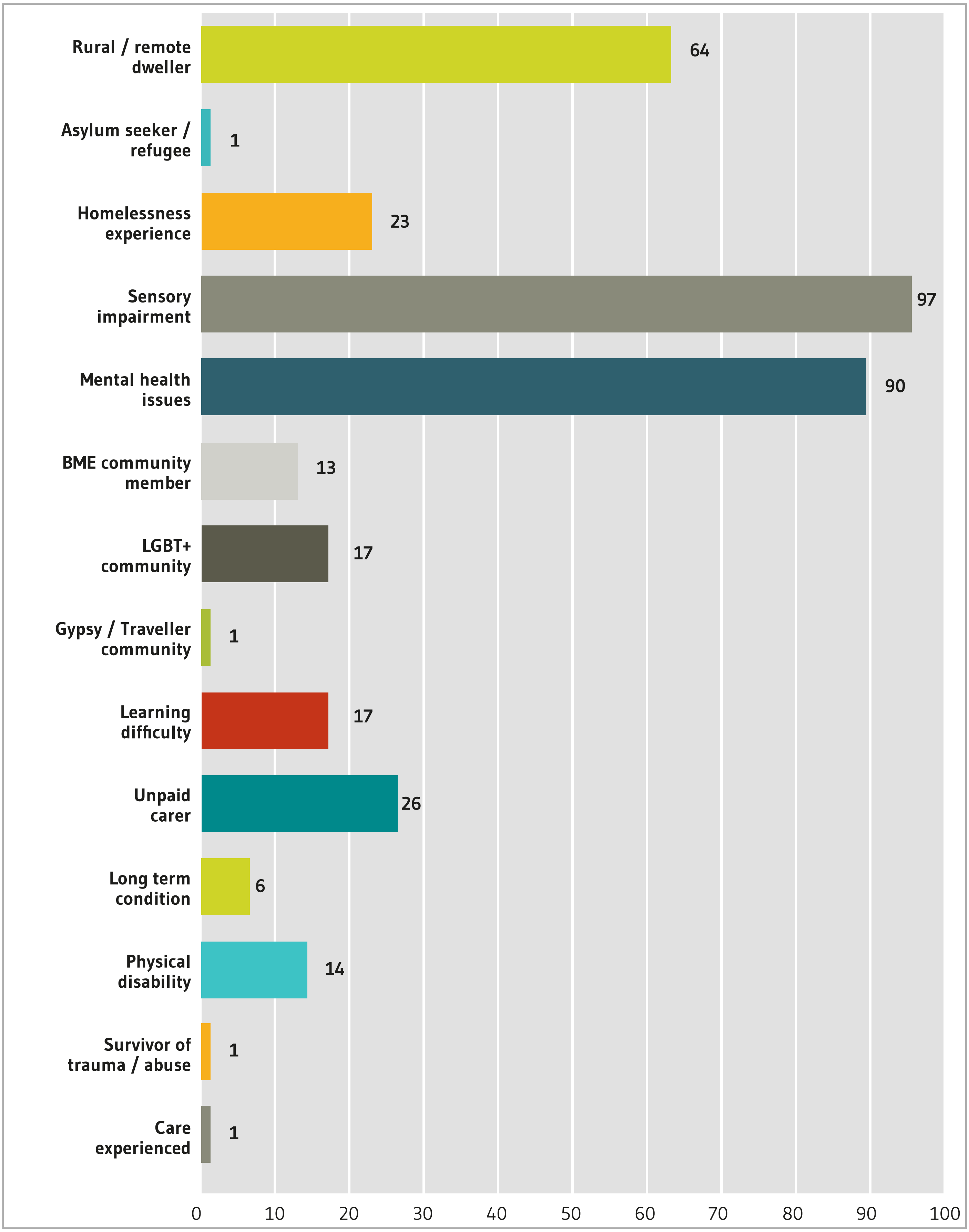


Employment Support Allowance	**Job Seeker’s Allowance**	**Child Tax Credits**	**Income Support**	**Tax Credits**	**Working Tax Credits**
63	8	2	13	3	2

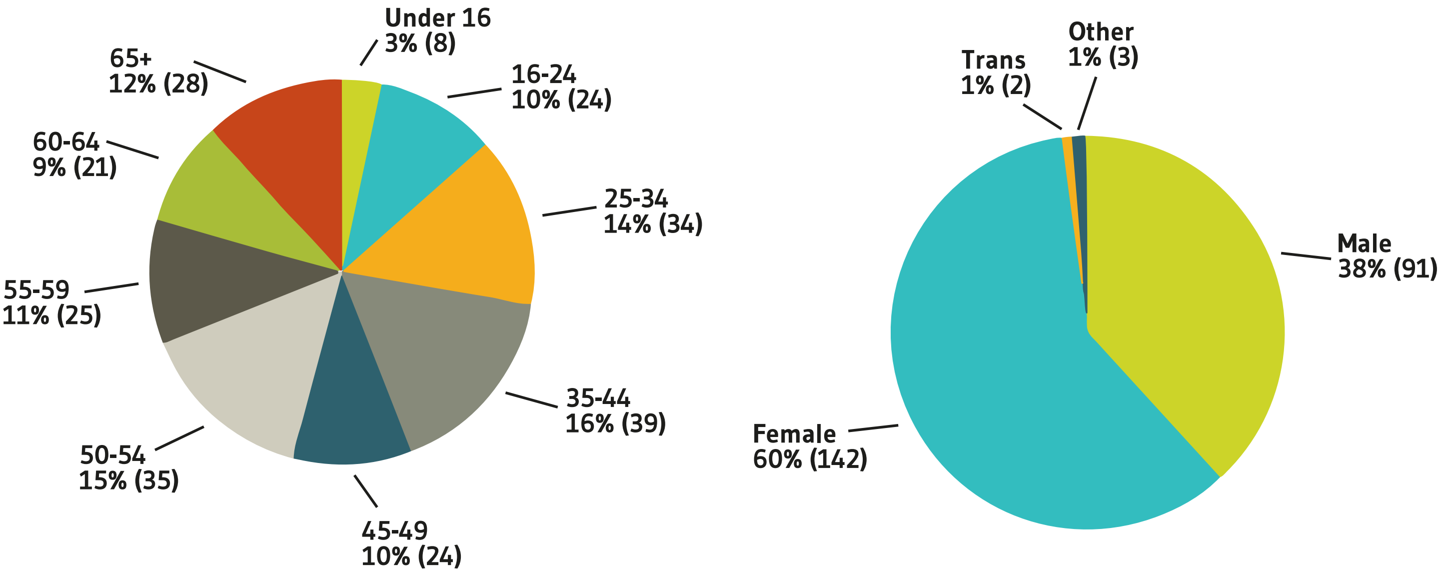
As the chart above indicates, respondents had experience of all the social security entitlements being devolved. To the left we can see that some respondents also had experience of entitlements that aren’t being devolved

How respondents self-identify

The survey asked respondents to indicate which seldom heard group(s) they identify as belonging to. This question was also multiple-choice and mandatory.



Age and gender identity of survey respondents



Focus group participants

97 people took part in 14 focus groups held around Scotland. Group details can be found in Appendix E and demographic data for participants is included in the separate group chapters.

- 4 people with experience of homelessness
- 4 unpaid carers
- 26 people with experience of mental health issues
- 7 people affected by sight issues
- 4 people affected by hearing loss
- 6 people with a learning difficulty
- 3 members of the BME community
- 18 members of the LGBT+ community living in rural/remote Scotland
- 16 members of the refugee/asylum seeking community
- 2 members of the Gypsy/ Traveller community
- 7 people with disabilities living in rural/remote Scotland

National stakeholder views

Key stakeholders that self-identify as seldom heard or work for/with seldom heard groups took part in a national stakeholder round table event.

As well as providing valuable advice and input to project design and delivery, we asked them: *"What are the important issues with regard to a new Scottish social security assessment project for you/your organisation/the people you work with/represent?"* Participant views – which were often reiterated in the survey and focus groups – are summarised below.

Awareness and understanding

- A national PR campaign should be organised by the Scottish Government with the Third Sector and others to challenge the stigma surrounding social security, help change the culture around it, and inform people about the devolution of powers – frame it as a human rights issue.
- Many people, for example older people, are often excluded and unaware they are eligible for social security and/or how to go about securing it.

Problems with the current system

- There is a great deal of inconsistency in the current system, which many people experience as very negative, traumatising, dehumanising and disempowering.
- The current system is overly focused on a medical model of disability; a new system should be much more focused on the social and human rights models, independent living, etc.
- The new system needs to look more closely at the nature of criteria/eligibility for a range of entitlements, not just PIP which seems to dominate the discussion at the moment. For example, Funeral Payments have become a lot harder to access since being administered centrally rather than locally.
- There seems to be a particular use of language and 'hidden information', which is used to confuse and intimidate people who don't speak English as a first language going through the assessment process. It's important to create an environment that puts people at ease.
- The current appeals process has individuals bouncing back and forth – appeals have a detrimental impact on people's wellbeing in the long term and cost more.

Oversight and improvement

- There needs to be a well-functioning complaints system to help reinforce a sense of trust that there is a commitment to dealing with complaints and addressing areas for improvement.
- The new system needs an independent scrutiny body to oversee it. At the moment the system is geared towards reducing fraudulent claims; instead it should focus on where there are obvious internal failings (as demonstrated by the successful appeals rate).
- The new system should have an integrated, ongoing consultation process with seldom heard groups.

Cross-sectoral approach

- The social security system, social care system, new employment system and health care system all interact with and affect each other. They need to communicate better with each other and trust each other. For example, money saved in healthcare could be invested in social security.
- The new Scottish social security process could tap into existing assets, for example community workers.

Culture, behaviour, attitude and skills

- In Scotland we often talk about social justice and to demonstrate this we need to radically evolve the social security system.

- Let's embed the human rights-based 'PANEL' principles and a human rights-based approach in every level of the system. There needs to be recognition that the system is dealing with human beings and that fair, equal and dignified treatment for all can be expected. Transparency is key.
- There needs to be greater consistency and trust across the system.
- Assessors must be properly (medically) qualified to ensure a good level of understanding of the claimant's situation/ diagnosis.
- Training from those with lived experience should be given to everyone involved in delivering the new Scottish system.
- People within the new system should also have equalities training – e.g. anti-racism training.
- People (assessors) working in the future assessment process have to be able to recognise that claimants will have good times and bad times. Fluctuating conditions have got to be recognised.
- There needs to be a fundamental change in the culture of assessment – people should assume they are going to be supported by the process rather than punished. Assessors need to be empowered to make decisions and understand that their focus is to provide people with support.
- A partnership approach is needed during the assessment, with assessors taking an 'I'm on your side' approach to claimants. Taking a stance of support like this can really help to change the dynamic and culture.
- We need to change the language in the assessment, and wider social security, process/ system. At the moment, there is a level of assumption that everyone is fiddling the system and it's important to challenge and change this.
- Private organisations should never be involved in the process – social responsibility cannot happen where money is involved.

Intersectionality

- Intersectionality comes to the fore with members of the BME community.

Assessment interviews

- An assessment meeting should not be needed if sufficient (medical) information has been provided by the application form and other supporting evidence.
- Applicants should not be required to participate in assessment meetings if their medical advice indicates they are too unwell to do so.
- Supporting people with chaotic lifestyles to turn up to assessment meetings can be very difficult – it would be good if the new system understood and supported this.
- People shouldn't have to travel far to assessment meetings. For example, some people currently have to travel to different cities, but their ability to do so is then used against them in the decision-making process.
- People should get greater information about their rights, for example that home-based assessment meetings are possible.
- Applicants should have access to notes taken by assessors and be able to take a copy away with them after assessment meetings.

Support/assistance

- Adjustments must be made and support must be available for all applicants with particular requirements, for example communication support such as digital note-takers for applicants affected by hearing issues, and a wider range of audio recording devices than currently permitted.
- For people who require temporary, rather than lifelong, social security, assessment should be focused on empowering them to explore self management and recovery.
- There needs to be easily accessible and available guidelines and information sharing for individuals going through the process so they know what to expect.

- GPs have a key role to play, but this role needs to be adequately resourced. They are specialist decision-makers, who provide qualified paper evidence for the assessor, so why is an additional assessment meeting needed as well as the information they provide?
- The new system should remove the volunteer cap of 15 hours – it is an important route to recovery but people are frightened to talk about it in case it is removed.
- The introduction of a Citizens' Basic Income needs to be properly discussed.
- Independent advocacy is now fulfilling a role that the system used to do – a welfare rights approach has to be the way forward for the new process.
- There is a bigger role for independent advocacy to play in the new system. Access should be universal; it should be a statutory right similar to that contained in mental health legislation.

Overall views of seldom heard people

Should there be an assessment process?

The majority of people who took part indicated that there should be an assessment process of some sort, although a small number said categorically no. Others indicated that alternatives to social security should be explored further, with particular reference made to a Citizen's Basic Income.

Fairness

Many people believed that some sort of assessment is necessary to ensure that social security is fairly directed at those who genuinely require it, and to avoid fraud.

Lifetime entitlements and reviews

There was a general consensus amongst nearly all participants that people diagnosed with lifelong or life-limiting conditions should be granted lifetime entitlements. They should only be required to take part in one assessment (i.e. no review or reassessment). For other applicants, reviews have to be less frequent than they are currently and take place when a major change in the person's condition occurs, based on information from their own (medical) advisors.

Assessment by application form only

Most people believe that in many cases applications could be made using only an application form with supporting (medical) evidence – where required – that should come from people who know the applicant well (e.g. a doctor, social/support worker, family/unpaid carer). Several people expressed highly negative views and experiences of unnecessary and traumatic interviews and medical examinations, with unqualified or unskilled assessors, apparently designed to be punitive and catch people out rather than delivered in a supportive and empowering way.

> *"I think it's fair to assess all who apply in order to make sure allocations are for genuine situations and fairly distributed"*

> *"People with a lifelong condition should be assessed only once"*

> *"Not a face to face assessment with someone who is not even medically qualified but through a process of application forms and medical evidence from the person's own medical team who know them best. Medical professionals should be given time and suitable budgets for this as at present there is no means for this to happen on a wholesale basis. Sack all the DWP "medical" assessors and adequately fund a system where people can get full reports from their own medical support staff for the assessment process"*

Who should decide on eligibility?

People were asked who should decide if a person qualifies for social security in the new Scottish system. Respondents shared views on who should be the direct decision-maker(s) as well as those who should be involved by providing information to support the decision-making process.

Medical information and expertise

The majority of people indicated that where certain entitlements require medical evidence the decision-maker or information-provider must be qualified, medical experts, or people independently trained in the condition(s) experienced by the claimant. Participants shared stories about people's poor experiences of inexperienced and uninformed assessors, including those with health/medical training but not in a relevant field or specialism.

> *"Someone who is trained to make an objective decision"*

> *"A person who really knows the person's circumstances and needs"*

> *"A public servant or NHS staff, not a private company with a direct incentive to reduce payments."*

> *"There should be panels of people from differing professions and service users who decide on the various categories of payments"*

> *"Someone who has meaningful knowledge of a person's health condition(s), the compassion to understand those who don't articulate themselves very well (even if they seem to) and the absence of working conditions which bias against the above."*

> *"Decision maker would have to have in depth knowledge of assessment rules, as well as the time to complete assessment and an understanding of people's health/social challenges. This may mean that decision maker has to be more admin/benefits trained, but that it's made alongside a statement from someone who knows/has specialist knowledge re health/social situation of the individual applying, and that statement given some sort of 'strength'."*

> *"A qualified assessor employed by Scottish Government will work with claimants own health professionals and the individual. No more OT making decisions about mental health. Assessors should be trained in a specific field of disability to understand the complications & needs but most importantly will go on evidence presented by NHS Dr & staff & support workers."*

Trained specialists

People indicated the importance of ensuring that decisions are made by those with other specialist training, for example in inter-personal, interviewing and good communication skills like active listening; impartial and fair decision-making; and equalities-related training.

Those who know the claimant

Many people emphasised that those who know the claimant well should be involved, either as direct decision-makers or as information providers. This includes qualified health and non-health professionals, like social workers and social care providers, as well as unpaid carers/family/friends.

Panels

Some respondents believed that decisions should be made or informed by multi-disciplinary panels, comprised of people and professionals that know the claimant, legal experts, 'experts by experience', experts by training in the claimant's condition(s), and unpaid carers.

Independence and accountability

Independence and accountability in decision-making were key factors. Several respondents highlighted the problems in the current system caused by outsourcing assessments to the private sector. People believed decisions should be made by an impartial, non-profit body and based entirely on the claimant's requirements, rather than being driven by incentives or targets, financial or otherwise. Several people indicated that this would best be delivered by a state-run body overseen by the Scottish Government, while a few others recommended that local authorities or the third sector should play a leading role.

What help/support should be available?

Respondents shared their views on a wide range of options that should be available to support people find out about, access and apply for social security entitlements.

Information and communications

Easy access to clear and impartial information is very important. Information should be made available in a wide range of alternative formats (e.g. different languages – including BSL – online (chat), telephone, paper, face-to-face) and take account of people's different communication requirements. Applicants should be able to choose the format(s) that suit them best.

Better and wider public information/awareness is generally required about social security and what people are entitled to. Ways for people to find out quickly and easily if they are eligible should be made available, e.g. helplines and online, to reduce the numbers of those eligible who are still not in receipt of social security.

Information should also pro-actively be made available by a wider range of qualified and informed sources that people come into contact with, including public sector services (run by local authorities or health care providers) and the independent/third sector.

Before someone starts to undertake the application process, they should be provided with clear, accessible information in a format tailored to them about what will be involved and what to expect. Information about independent advice and support to help people navigate the system should also be made available and accessible to people at the start, and then throughout, the process.

People's different communication requirements must be accommodated, for example digital note-takers/palantypists, working loop systems, translators, scribes, etc., at each stage of the process.

> *"Interpreters - foreign language or BSL. Support to understand the assessment process and what to expect. To have a carer/family member/friend to support the person through the assessment. Offer support from Citizens Advice to help with the assessment e.g. having a drop in clinic or passing on details of the nearest CAB office."*

> *"Dedicated, fully staffed, telephone helpline. FAQ website, paper booklet posted to every claimant. Clear and easy to follow guidelines."*

> *"A working loop system is beneficial to anyone wearing a hearing aid or cochlear implant as long as their aid has been so enabled. Anyone who is applying due to a severe hearing loss is very likely to also need a trained lipspeaker or ENT (note taker/palantypist). Applicants whose language of communication is oral English will not benefit from the presence of a BSL interpreter unless they have chosen to learn this language."*

Personal support

Many people indicated that personal (one-to-one), experienced, informed and knowledgeable support should be made readily available to every claimant. Personal support is needed to help people better understand and navigate the social security system. Some people noted that peer support – either one-to-one or via support groups – would be helpful. Others noted the importance of independent support. Some people mentioned support from local authorities and the third sector.

Personal support may require home visits. It should also be available and accessible at any point in the assessment process. Timings throughout the application and assessment process should be flexible if someone requests personal support part-way through and this takes time to put into place.

> *"One-stop drop in support. Advisors available to assist in informing of support available for specific situations. Support in completing forms & help with providing correct evidence etc. Almost a pre-approval check, so to speak. Similar to passport process whereby all forms & documents can be checked as completed correctly and correct/appropriate evidence provided. Save time/money rejecting applications not completed correctly or missing information. The provision of one-stop drop in advisors should be non-judgemental, unbiased and appointments or drop in can be sought in a timely manner."*

> *"More training for people who have anything to do with the assessment process about the conditions that they are making decisions about .A more sympathetic attitude towards people with disabilities and mental health problems instead of humiliating them often aggravating the conditions that they suffer from. More recognition and finances for carers."*

> *"Independent Advocacy & input from healthcare & SW professionals with client at centre of process. Remember : Nothing about us, without us."*

Application forms

The importance of personal support to help complete application forms was particularly mentioned. Many people referred to independent support, while others suggested peer support, local authority workers, social care providers, health professionals and family members.

People should be given a choice of options of how to complete and submit application forms (e.g. online, paper, in-person and over the phone), and communications support made readily available where required. People should have the option of completing forms at home, again with personal support if required. Online forms should come with the option to save and continue later.

Application forms should be accompanied with information that signposts applicants to independent advice and support providers. The forms need to be clear and simple, and kept as short as possible. While recognising that there may be a bureaucratic need for a generic form, several people noted that the questions should also be relevant and tailored to the individual, e.g. for those with mental health issues. A common issue raised by many respondents was that the current application form is overly complex and too long. Some people noted that if the form was well produced they would not require support to complete it. There was also a sense from some participants that the current form – much like the overall system – is designed to 'trick' people out of their entitlements.

Some people noted the need to reduce the number of forms that are required for different entitlements, which requires repetition of the same information. Others took this opportunity to restate that for some conditions/diagnosis, applying for social security should only need to be done once via a form with supporting information, i.e. no assessment meeting or reviews would be required.

Independent advocacy and advice

Access to independent advocacy and impartial advice – from the Citizens Advice Bureaux and the third sector – must be readily available to everyone applying for social security. Some respondents noted current advocacy and advice providers require better funding and resourcing. Advocates and advisors need to be well informed and knowledgeable about the social security system and ideally the different conditions that people may be diagnosed with.

Local authorities

Some people noted that information and support should be provided by local authorities, with particular reference made to local authority welfare rights officers and social workers.

What needs to happen before, during and after assessments?

Human rights approach

Many people indicated that the decision-making process should be fair, transparent and accountable. Implicit in this recommendation is that the new social security assessment process should take a human rights based approach.

Information and communications

People need to be fully informed and aware of their rights, what to expect and when, throughout the social security assessment process in a clear and timely fashion. The different steps and likely duration of the process must be set out and the criteria upon which their application will be and has been assessed must be clear, fair and transparent.

Information and communication should be tailored to the individual's requirements and available in a range of formats from a variety of sources – it should be up to the claimant to choose those most appropriate for them.

Once an application form has been received, quality lines of communication should be established by a (named) assessor with the applicant – again, using an accessible and acceptable format.

Assessors need to be given the time and resources to properly review applications and gather any additional information that may be required, e.g. medical reports, but this should be as speedy a process as possible and applicants must be kept informed of progress. Some people suggested a 'track my order' style checking system.

Clear information and communication supports during assessment meetings, if required, were seen as essential. The meeting format should allow for the assessor and person being assessed to regularly check their understanding of what is being discussed and agreed, irrespective of diagnosis but particularly so if interpreters or other communications support is being used.

After an assessment meeting, if one is held, information and communications need to be extremely clear and easy to understand. The assessment agency/personnel need to ensure they regularly keep people informed while decisions are being made – with communications tailored to people's requirements. Once a decision has been made it needs to be thoroughly but very clearly explained.

> *"People should be fully informed as to the nature and purpose of the assessment, likely outcomes and effect these may have on a person. People should be reassured that the goal is to help them get their entitlement, not to save government money."*

> *"assessor should have read paperwork, done homework, adopted a professionally neutral stance and acknowledge the stress of being a claimant often adds to the illness they are having to prove or demonstrate."*

> *"Ultimately it MUST be the responsibility of the NAMED assessor to ensure all the relevant information is gathered to ensure a full assessment is completed. The applicant MUST be made aware of who is responsible for their assessment. Having ONE clear assessor would mean the applicant wouldn't be lost in the strange limbo where maximus (for example) blames the DWP and the DWP maximus for the decision made. This would ensure clarity. Applicants must have access to independent advocacy before, during and after the assessment. Make sure staff are well trained and supervised to ensure consistency between assessments. Doing this well will reduce the need for expensive reviews/ challenges to inaccurate assessments"*

Personal support, independent advocacy and advice

As described in the previous section, people should have signposting and easy access to independent sources of personal support, information, advocacy, advice and guidance throughout the assessment process.

The opportunity to be accompanied and supported by anyone of the person's choosing at assessment meetings is seen as a very important element.

Deadlines and timelines

People indicated that the deadlines imposed on submission of a completed application form must be reviewed and changed, if not completely abolished. There are often good reasons why people fail to meet the time limits that the current system does not account for.

Application forms should be processed quickly, fairly and professionally, to ensure claimants do not have to wait for their application to be approved.

Final decisions and payments need to be made promptly and quickly. Some suggested a decision could be indicated at the end of an assessment meeting, if there is one. Others suggested a time limit be imposed on decisions.

> *"Many people are frightened of the word assessment having a conversation would be better and my answer is yes people should have a conversation"*

> *"All assessments should be allowed to be recorded by the person attending, people should always be allowed a representative or advocate. Full needs should have been ascertained before the assessment goes ahead so that it is done appropriately, timely and in a person centered way."*

> *"Rather than making an assumption, assessors should clarify whether they have correctly understood the person's response. Practice in a way that is informed by research and other evidence, so that detrimental effects are avoided. See people on time"*

> *"Assessors need to work in a person centred approach, to listen to what the individual is saying and not dismiss them. Assessors need to understand some people might be very anxious about coming for an assessment so they need to reassure them about the process before they start and to show that they understand the person is anxious and let them take their time to respond. To take the view that individuals are the experts on their own health conditions rather than seeing themselves as the experts. They need to take on board what the person says about their health conditions/disability not just going with their view of it. To have information in the right format for the person, have an interpreter there is necessary."*

> *"Advocate and supporter can accompany and help throughout. Information and intelligence from own GP and medical specialists who know the claimant should be prioritised and not treated as inferior or suspect."*

> *"Keeping claimant informed regularly. It's a very stressful process."*

> *"Comfortable environment, friendly staff, good knowledge from staff"*

Financial support and payments

People did not think that social security applicants should have to pay for information to support their claim. Some people also think that applicants should have access to financial support while their applications are being assessed to avoid hardship.

Once a decision has been made, payments should start promptly and should continue until any appeal process is finally concluded. This includes access to other support, e.g. Motability vehicles. Some people described the hardship and social exclusion experienced when vehicles were automatically removed before an appeal could be lodged under the current system.

> *"each side should have equal access to any reports or paperwork or information; there should be a clear challenge procedure which does not assume fault on part of either party."*

> *"Clearly spell out how the figures have been worked out. Deductions aren't always clear and should have to be supplied only on request. Then people can better judge whether they've been awarded the correct amount or if errors have been made despite supplying all the relevant information. Alternatively, having a reliable online calculator or other publicly available means of checking the award would be most helpful."*

> *"People should be given a copy of any paperwork filled out. And also of the tape recording or video. A decision should be made asap. All reasons for decision must be clearly stated with methods of appealing if needed."*

> *"Payment needs to be as quick and smooth as possible and explained accurately. DWP's award letters can be cryptic at times and leave a lot open to interpretation which is not helpful to someone with mental health problems or indeed for those of a different language and cultural background. If there are doubts and an appeal has to be made, this should be as smooth and as quick as possible with Advisor/Advocate support if necessary. For the uninitiated, new claimants, "fragile/vulnerable" and those of a different language the DWP process IS EXTREMELY daunting!!!! For those having been through "the system" before it remains EXTREMELY daunting and in fact VERY un-user friendly!"*

> *"Clear simple accessible information and advice on how to access education / training / employment or pre-employment options"*

> *"If a person has been assessed as having a lifelong condition, a progressive condition or a life limiting one, they should not need to be assessed again as this is a waste of time and resources"*

Culture, behaviour, attitudes, skills

Many people referred to the attitude, behaviour and skill-set of the people tasked with carrying out assessment meetings. Meetings should be carried out in a fair, transparent, compassionate and humane way. Some people talked of it being more like a 'conversation' than an 'interview'; designed to treat people with dignity and respect, and support them to understand and claim their entitlements, rather than take a suspicious, dismissive or punitive approach.

Assessors should be aware that some people may downplay their disability on forms and in meetings because they take a more strengths/assets-based approach. This should not detract from their right to social security entitlements. Again, people stressed that decisions based on medical evidence should use information provided by the professionals known to the claimant.

Many people believed that assessors need to demonstrate excellent interpersonal and communication skills, as well as expertise in the diagnoses that the person experiences, e.g. mental health issues.

Several people noted that assessors must be aware of, and have skilled responses to, how stressful and upsetting the assessment meeting can be for some. Others shared their experiences of being assessed by general health professionals rather than mental health experts that involved intrusive, upsetting or irrelevant lines of questioning.

Assessment meetings

Many people believed assessment meetings are often unnecessary, for example if someone has a lifelong or life-limiting condition, and that an application form, with supporting evidence where required, should be enough information on which to assess a claim. However, some believed that applicants should have an assessment meeting if they request one.

If a meeting is required, they need to be designed and delivered in a person centred way, tailored to the individual claimant rather than a 'box ticking' or 'one size fits all' exercise. The booking system should be flexible and person centred. Respondents suggested different options, including an online/telephone booking system or multiple choice questions on the application form.

Assessment meetings should be held in a location and venue convenient for the claimant, including in their own home if desired. Several people noted that assessment meetings can be held very far distances from where they live (e.g. Edinburgh meetings for people living in Dumfries). There needs to be greater flexibility in the scheduling and duration of meetings. Some people, e.g. those with mental health issues, take medication that means morning appointments are very difficult to attend.

Assessors should take time to prepare for assessment interviews and ensure all the relevant information is available and reviewed in advance. Prior to the meeting any communication or accessibility requirements should be verified and appropriate, working equipment or support provided free of charge. People should be supported with travel, travel costs, child care and child care costs to take part in meetings. The meeting room environment should be prepared to ensure it is comfortable, warm, etc. There should also be opportunities for regular breaks throughout the meeting.

Several people noted that an assessment meeting should not be used to reiterate information that is already available in the application form and supporting documents. Similarly, additional medical examinations should not be carried out if information is available from the person's own health professionals. Several people noted that more weight needs to be given to the medical and other supporting information that accompanies someone's application than is done so at present. Many people noted how irrelevant current tests are, such as being able to walk unaided for certain distances.

Some people suggested that the social security agency should use this opportunity – if they haven't done so before – to inform claimants of other entitlements they may have a right to. People should also be signposted/guided in a supportive and strengths-based way to other opportunities and support in related areas, such as education/training, employment, wellbeing.

Many people noted it would be good for assessment meetings to be video recorded. Others think that applicants should be able to review the notes taken by assessors at assessment meetings, sign to indicate whether they agree with them or not, and be given a copy to take away.

Appeals

In the event that someone's application is denied, a speedy appeal process is essential, with clear information about what it entails and the support available.

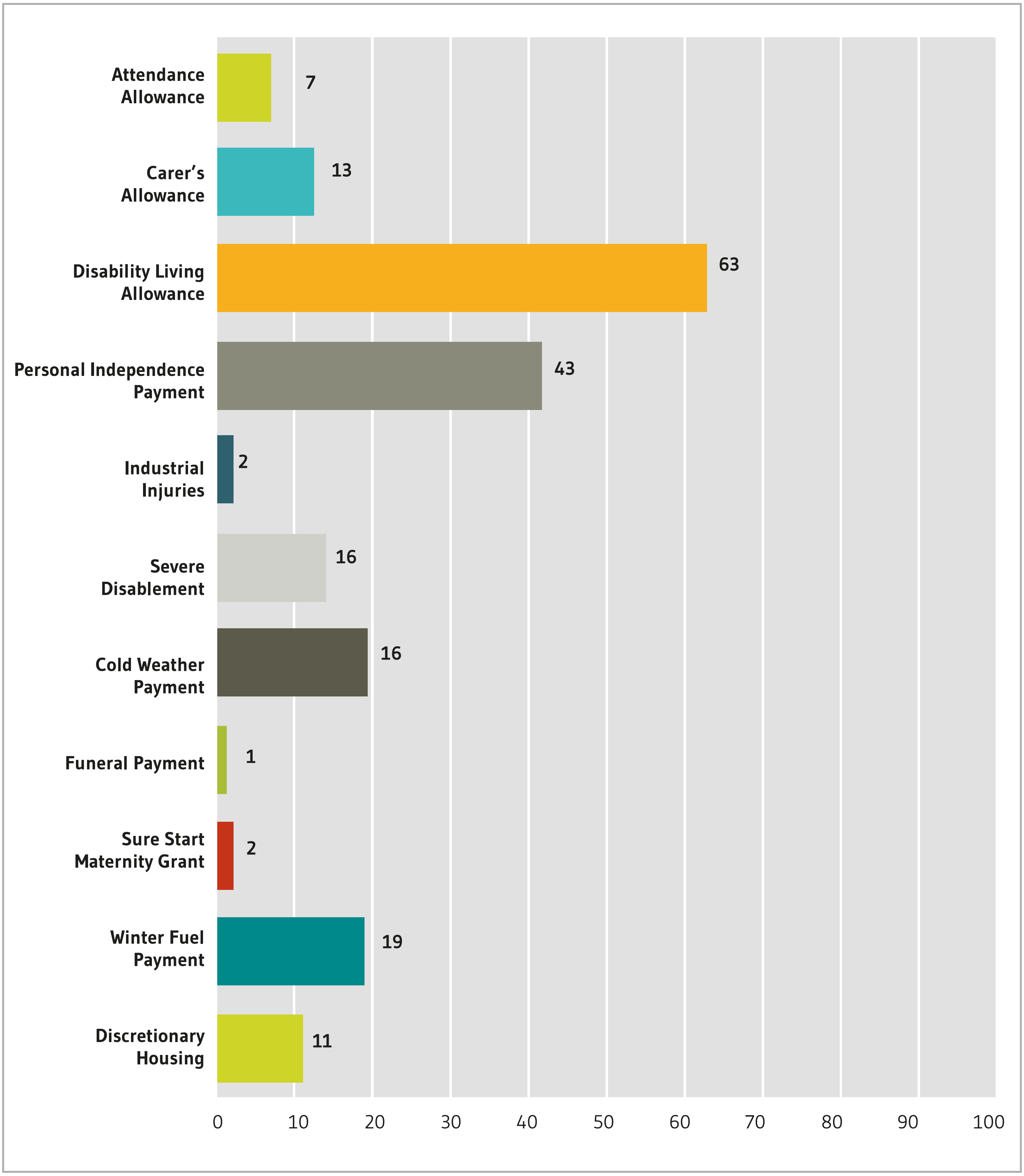
Signposting/guidance and quick, easy access to third party/legal support should be made readily available (not just appeal but also moral/wellbeing support).

People should be given longer to appeal against a decision, to take account of different requirements and communication difficulties. Independence and accountability in the appeals process is essential.

People living with sensory impairment/ multiple conditions

Survey respondents

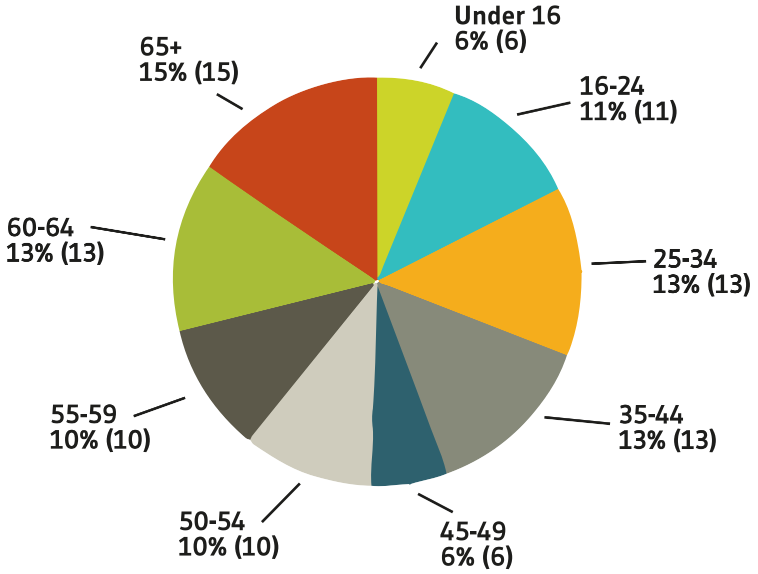
Experience of social security



Self-identification

Answer Choices	Responses	
Rural/remote dweller	23%	22
Homelessness experience	7%	7
Sensory impairment/multiple conditions	100%	97
Mental health issues experience	32%	31
BME community member	5%	5
LGBT+ community member	5%	5
Gypsy/Traveller community member	1%	1
Learning difficulty	2%	2
Unpaid carer	2%	2
Long term condition	3%	3
Physical disability	2%	2
Survivor of trauma/abuse	1%	1
Total Respondents: 97		

Age and gender identity



60 per cent female

40 per cent male

Focus group participants

11 people participated in two focus groups for people with sensory impairments organised in partnership with RNIB Scotland and Action on Hearing Loss Scotland. Participants had experience of DLA, PIP and ESA. They also self-identified as having lived experience of mental health issues. Seven women and four men participated, in the 16-24, 35-44, 50-54, 55-59 and 65+ age groups.

Views

Eligibility

It was suggested that GPs or other health professionals could have a much stronger role in supporting people with sensory impairments to access social security. Doctors and audiologists could send letters to the government noting the long term condition and that this is not going to change. For people with hearing difficulty this could involve an audiogram, whereas people with visual difficulty suggested that verification of registration could be utilised as a passport to support.

Some participants felt that more than one person should be involved in the decision-making process. Tribunals require three people, including a health professional, to make the final decision. People should also be told during the assessment process how long they are likely to have to wait to find out about the decision that has been made.

Information and communications

A checklist of information on the assessment and about social security entitlements should be provided to applicants in a variety of ways, depending on how individuals wants to receive it. Some participants highlighted that they had difficulties with reading English and that letters they received were therefore difficult to understand. People said they much prefer face-to-face support. Customer portals should also be made available through which you can book a timeslot and include additional comments such as "I require an interpreter".

Interpreters should be available to support people during assessments, but assessors should also be sensitive to the needs of people with sensory impairments (e.g. facing people with hearing loss when you are speaking as otherwise they will find it difficult to lipread). It was suggested that people with sensory impairments could be involved in the assessment process for other people with sensory impairments as they "understand".

People with hearing loss suggested that any new assessment process should recognise the role new technology can play in helping the decision-maker and the applicant. Some examples included communication via BSL interpretation on video, the use of FaceTime and an online system with an interpreter.

Assessment meetings

People with visual difficulties noted that assessment meetings shouldn't just be a process to go through a form. If this is the case then this could be better done by phone.

Independent advocacy

People generally preferred face-to-face meetings but advocacy support during assessments was seen as offering people with sensory impairment a guide when they feel stressed or nervous. Some people said that advocacy made it easier because they understand the needs of people with sensory impairments as well as the welfare rights context.

Deadlines and timelines

Some people suggested that more time needed to be built in to allow people to accurately complete the forms. In some circumstances gathering evidence from doctors and other health professionals can take time to get information that will help people in their assessment process. Additional time needs to be factored in to support people in these circumstances.

Some people highlighted the negative impact it had on their lives if social security was not made avaliable to them in a timely manner. In most circumstances this led to them relying on family members for support.

> *"People being helped to represent themselves alone is not in the least adequate support. Many, if not most, people would not be willing or able to represent themselves. This does not preclude them being able to speak up for themselves at some points during the process."*

> *"A working loop system is beneficial to anyone wearing a hearing aid or cochlear implant as long as their aid has been so enabled. Anyone who is applying due to a severe hearing loss is very likely to also need a trained lipspeaker or ENT (note taker/ palantypist)."*

> *"In my case, I would need a home visit as I can't travel to an assessment centre because of my disabilities. Support should be available for the assessment to be carried out at home in the case of someone with complex disabilities."*

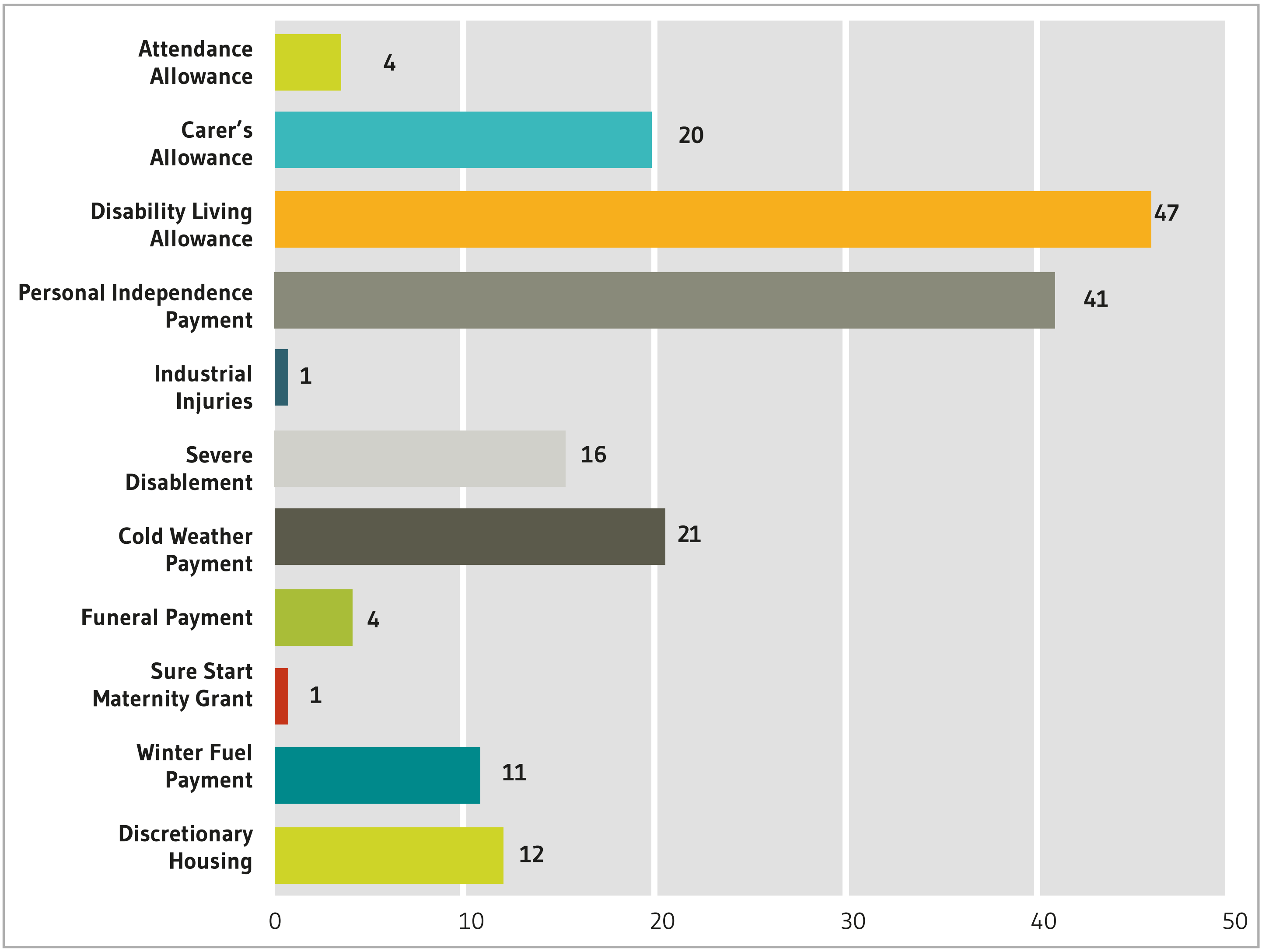
> *"Keep the claimant apprised. Acknowledge receipt of correspondence as a matter of course - as so much seems to get "lost". Give genuine (as opposed to wishful) estimated times by which relevant actions will be taken."*

> *"For people to be told how long they will have to wait to get a decision, what to do if they don't agree with the decision and for a reply to be send out as soon as possible."*

People with lived experience of mental health issues

Survey respondents

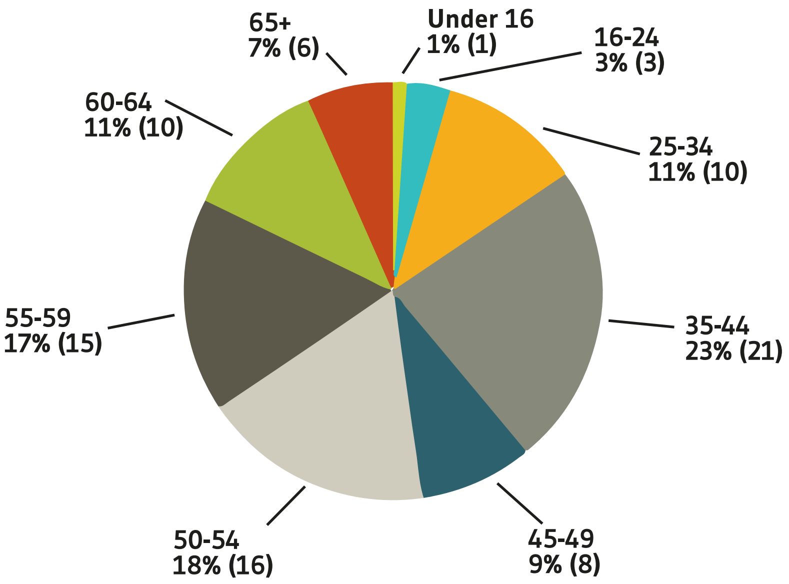
Experience of social security



Self-identification

Answer Choices	Responses	
Rural/remote dweller	27%	24
Asylum seeker/refugee	1%	1
Homelessness experience	16%	14
Sensory impairment/multiple conditions	34%	31
Mental health issues experience	100%	90
BME community member	9%	8
LGBT+ community member	10%	9
Gypsy/Traveller community member	1%	1
Unpaid carer	2%	2
Long term condition	6%	5
Physical disability	2%	2
Survivor of trauma/abuse	1%	1
Total Respondents: 90		

Age and gender identity



64 per cent female

32 per cent male

2 per cent other

1 per cent trans

Focus group participants

Three focus groups with 26 people with lived experience of mental health issues were carried out in partnership with HUG Action for Mental Health. Participants came from across the Highlands and Islands region. Two groups were gender-mixed and one was a women-only group. As well as lived experience of mental health issues, participants identified as living in rural or remote Scotland and having lived experience of homelessness. Participants had experience of a range of social security entitlements, including DLA, PIP and ESA.

Views

Applications and reviews

Some participants identified that an assessment process was important for many people in establishing what their entitlement was and making sure that genuine claims were processed. Others thought that assessments were intrusive and that information used in them could be identified from other, existing sources such as GPs notes and filling in forms.

One participant had previously had their eligibility established without the requirement for a face to face assessment. This had required information to be submitted by their psychiatrist, psychology and GP. Some people said that their experiences of other assessment processes aimed at establishing eligibility, e.g. self-directed support, were better.

Some participants said that anyone who currently receives entitlements should be automatically entitled to the new forms of social security. This should include entitlement to passported benefits.

Some participants noted that assessments could be helpful in establishing changes in a condition, e.g. relapses. However, repeated assessments for people with progressive conditions should only be about establishing further entitlement.

Eligibility

Participants suggested a number of different ways of carrying out an assessment process, including the creation of a team of people who live with long term conditions and impairments themselves who are trained to do assessments. Others felt that NHS personnel should be involved.

Medical professionals should be involved in supporting assessments, but tracking down the information yourself can be stressful. This information should also be accessible to the person making the application.

One participant suggested that a medical passport could be generated that holds all your medical details. This would be possible for the individual to see and control and enables the person to be involved in the process, as well as establishing entitlement to other types of support and sharing information with other agencies. Participants felt that there should be greater levels of integration of the information held by professionals about people who live with long term conditions.

Application forms

Focus groups were ambivalent about how long the assessment form should be. People with both physical and mental disabilities felt the form filling process should be shorter, whilst those with mental health issues alone (and thus no visible disability) felt the opposite. Some felt that a longer form enabled them to go into more detail and tell their own story. It was considered that a range of "repetitive" questions could be removed from the existing forms that could enable people to have a better experience.

Personal support, independent advocacy and advice

Some participants identified a range of practical support which should be made available to people going through the assessment process. One person identified people with Post Traumatic Stress Disorder as having particular support requirements during assessments.

Citizen's Advice Bureau support, Job Centres, local authority welfare rights officers and independent advocacy were all suggested. Increased awareness of these types of support is required for people ahead of going through any assessment.

Culture, behaviour, attitudes and skills

Some participants said that assessors needed to be better informed about the person's experiences before any assessment process started. Assessors should also recognise that people's experience of mental health problems one day can be different from the next. Female participants, particularly those with lived experience of trauma/abuse, were strongly in favour of being able to choose the gender of an assessor.

Independence and accountability

Some participants were keen to stress that private organisations should not be involved in determining eligibility.

Assessment meetings

Travel expenses were identified as an area of concern and any new system should make sure that people are able to apply for them in order to attend an assessment meeting. Some people said that they were unable to travel on buses so there should be an opportunity to get expenses for other forms of transport.

Deadlines and timelines

More time should be built into the system to make a claim for entitlement. Some people had experiences where they had waited two weeks for a form to arrive and then were only left two weeks to complete and return.

Financial support

Some people felt that payment process needed to be speeded up or interim awards made straight away to make sure people do not experience gaps in support.

> *"My GP statement for PIP included breathlessness/pain, but assessment stated 'we've decided you don't have breathlessness or pain as not on regular medication for them' (true for pain, as muscle pain relieved by rest; but am on medication that affects breathlessness but assessor didn't recognise as such."*

> *"You should be able to ask for assistance if required and time should be given for you to access it. PIP assessment letter had very tight deadlines which made it hard to access help in a timely manner."*

> *"All information should be given upfront - not after someone has applied (i.e. not requiring people to disclose details such as savings before telling them if they're eligible)."*

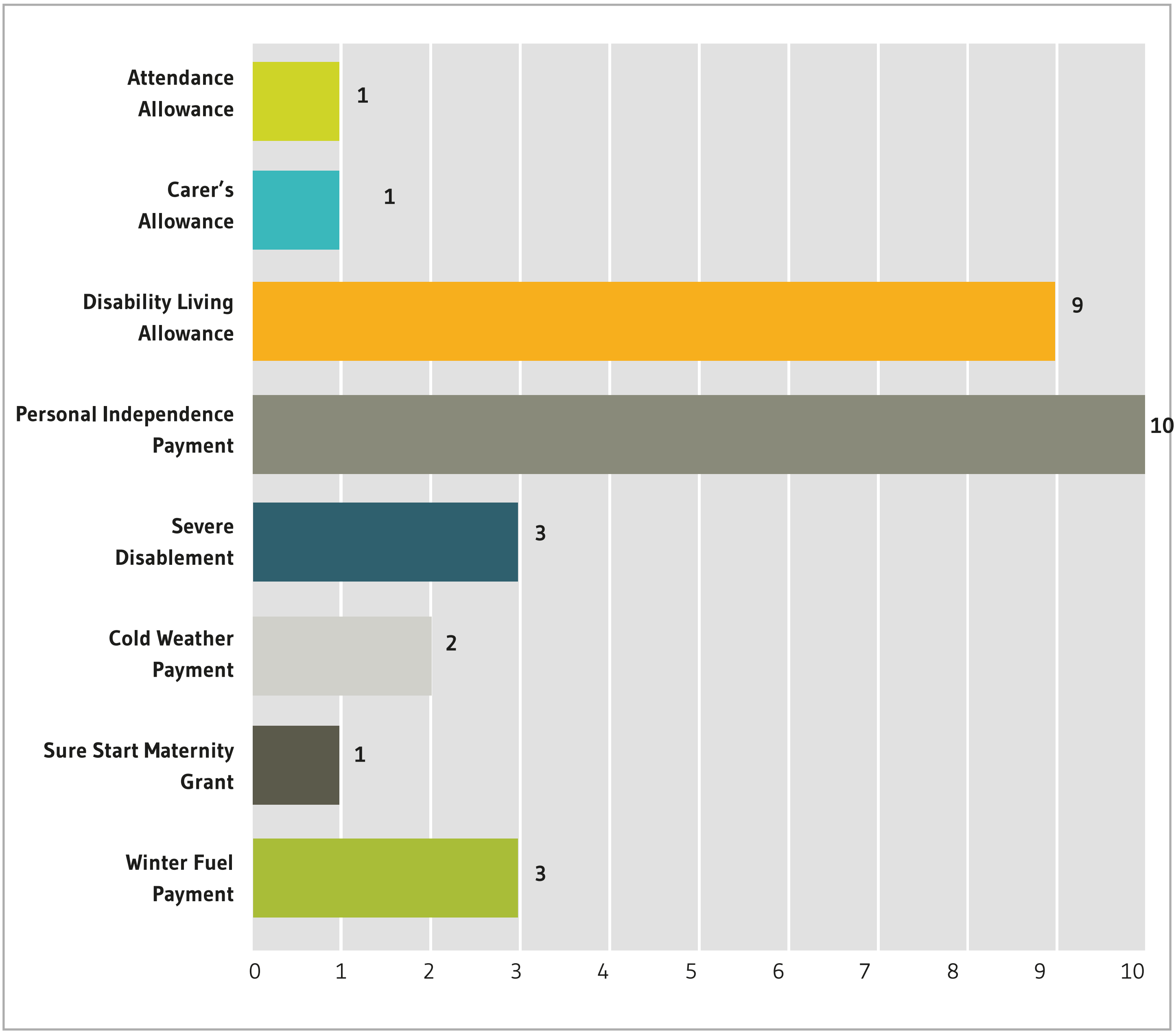
> *"Personal experience informs me that those with a mental health issues have reduced access as they will often not be able to handle or endure processes that are essentially negative. (i.e. Routinely handled in such a way as to eliminate or minimise payments regardless of the actual needs of the applicant)."*

> *"There should be clear accessible information regarding the process, the criteria, the timescale etc - in different languages and formats. A person may need someone to help complete an application - who should be independent of the person undertaking the assessment."*

Members of the LGBT+ community

Survey respondents

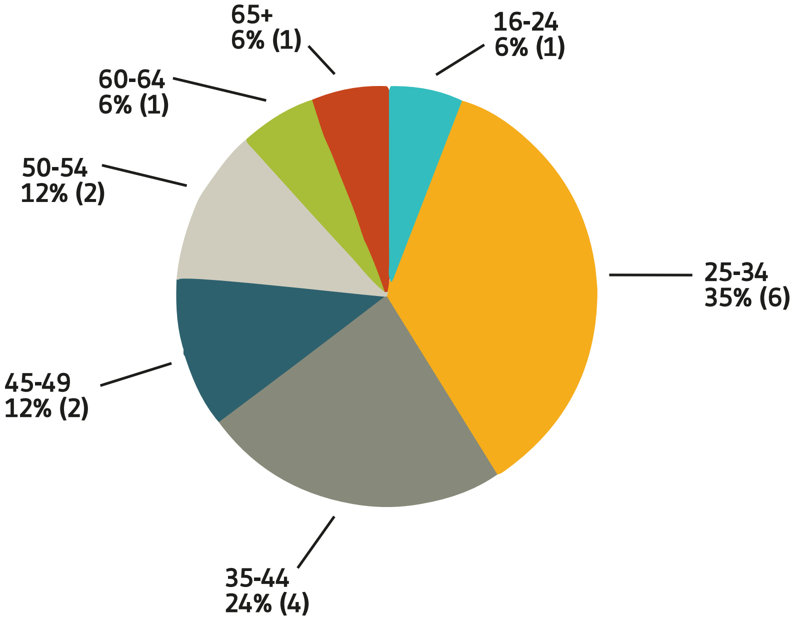
Experience of social security



Self-identification

Answer Choices	Responses	
Rural/remote dweller	18%	3
Homelessness experience	41%	7
Sensory impairment/multiple conditions	29%	5
Mental health issues experience	53%	9
LGBT+ community member	100%	17
Learning difficulty	6%	1
Long term condition	6%	1
Total Respondents: 17		

Age and gender identity



35 per cent female

41 per cent male

12 per cent trans

12 per cent other

Focus group participants

The ALLIANCE organised two focus groups for people who identify as LGBT+ in partnership with Dumfries and Galloway LGBT Plus. Both groups comprised nine participants each. Participants had a wide range of social security experience, including Attendance Allowance, Carer's Allowance, DLA, PIP, Severe Disablement Allowance, Cold Weather Payment, Winter Fuel Payment, Discretionary Housing, JSA, Child Tax Credits, Child Benefit and Pension. As well as belonging to the LGBT+ community, participants self-identified as having lived experience of mental health issues, learning difficulty, homelessness and living in rural or remote Scotland. Participants identified as belonging to the 35-44, 45-49, 50-54, 60-64 and 65+ age brackets. 14 participants identified as male, three as female and two as trans.

Views

Applications and reviews

Most members of the LGBT+ community echoed the overall view of seldom heard people that there needs to be some sort of application process, but that for lifelong or life-limiting conditions then a one-time application using a form with supporting information (e.g. GP's report) should suffice. People suggested that the General Medical Council could decide the list of conditions that would qualify for this.

Some focus group participants indicated that face to face assessment meetings are often not required – they either reiterate information that has already been covered by the application form and supporting information; or could be replaced by a telephone interview.

There were a range of opinions with regard to the timing and frequency of reviews. Some people recognised the need for reviews because improvements in medical science can change the prospects for some conditions. Others thought there should only be a one-time assessment and/or alternatives to social security, such as a Citizen Basic Income. People agreed that if there is a review process it needs be intelligently designed, less stressful and take common sense into account.

Eligibility

Members of the LGBT+ community believe that qualified medical professionals, including GPs, should have a much greater say than they do at present. Some people also thought that, if applicable, paid carers and support workers should be involved in the assessment process.

Information and communications

Members of the LGBT+ community stressed that information should be accessible and that the new agency should make the effort to actively provide and equip claimants with information on the system and what they may be entitled to. For example, if told at an assessment meeting that you are not eligible for a certain payment, the assessor should inform applicants of all the other payments they may be entitled to.

Information should be provided in alternative formats, including written and over the phone. It also needs to be made easier for people with different requirements, e.g. visual impairments, to complete application forms.

Culture, behaviour, attitudes and skills

Members of the LGBT+ community indicated that there is little trust in the existing system and this needs to change. For example, participants in the Dumfries focus group noted that assessment meetings there are held in an upstairs venue. In order to gain access, people have to ask for a key to use the lift. If they use the stairs instead, they are penalised for being able to use stairs.

Some people felt that assessors can be dishonest in their approach – they will appear to be supportive and sympathetic at an assessment interview, but then the applicant receives a rejection letter. As with other groups, members of the LGBT+ community noted that the assessment meeting should be more of a conversation than an interview.

Participants noted that there needs to be more transparency, compassion, dignity, respect and empathy in the future system and its personnel. The new system also needs to be more person centred. A comparison was made with other professionals and services, for example, GPs, social workers and Occupational Therapists – people don't need a points system to access these services, so why should they in order to access social security?

The Scottish Government should invest in training staff to help create a mental shift. Assessors need to be better trained to ask informed questions and recognise that someone who looks healthy isn't necessarily well. Assessors also need access to good quality information about different conditions, for example HIV, symptoms and the side-effects of medications.

Members of the LGBT+ community put forward two proposals for a new assessment process. Firstly, they wondered if the system would work better if the current process was flipped, with all applicants starting out on maximum points that are then deducted, rather than starting at zero and having points awarded. Secondly, they wondered if the current points system would be better if replaced by a sliding scale.

Independence and accountability

Members of the LGBT+ community agreed that the new assessment process should not be run by a private company with targets to meet. They advocated making the new Scottish social security agency a state organisation.

They also proposed creating a customer feedback system that would be organised by locality so that information could be fed back to the community and would encourage accountability.

The creation of an Ombudsman service was also regarded as highly important in the new system.

Application forms

Members of the LGBT+ community thought that the application forms need to be condensed and made easier for, e.g. people with a learning difficulty, to understand. There should be options to give fuller answers than a simple tick box YES/NO, which doesn't always work for people. People should be able to complete forms online, with options to save and make changes before submitting.

Some people suggested that application forms could be tailored to localities. Others suggested that the language used in forms needs to change to make them more accessible. Participants suggested that application forms should indicate where the applicant can access independent support to complete it.

Personal support, independent advocacy and advice

Some members of the LGBT+ community expressed the view that if the new system is designed more intelligently then less support would potentially be required by those navigating it.

However, they also felt that it was essential to have advocates available to provide support if they were needed, particularly for people with long term medical conditions and/or learning difficulties. People should be available to help with decision-making and interpreting information in, e.g. application forms, etc.

There should be an automatic entitlement to have a friend, relative or advocate present at assessment meetings, whether held in the person's home or in another venue. It should be someone that knows the system and can speak on the applicants behalf if need be, should they get panicked or forget.

Focus group participants noted that while the CAS offer good advice, they have limited ability to offer representation at meetings.

Assessment meetings

Focus group participants proposed the idea of having a national social security agency located in central Scotland, but with regional hubs around the country that would feed into it. These would be located in the community and comprised of community representatives.

Applicants should receive a pack beforehand to help prepare for the assessment meeting.

Focus group participants also agreed that there is not enough local provision for people living in rural or remote Scotland. For example, one participant in Dumfries was required to attend an assessment meeting in Edinburgh but was later informed they could have requested a meeting at a more local venue. Another Dumfries resident with ME had to attend a PIP assessment meeting in Carlisle at 8.30am, which was extremely difficult.

As with other seldom heard groups, members of the LGBT+ community believed there needs to be far more flexibility concerning the location, date and time of assessment meetings. A person centred approach should be taken with the individual able to choose a home visit if preferred, and a date and time that suits their condition and life. If a home visit isn't desired, then the meeting venue should be local to the applicant. Transport support should be provided.

The environment of assessment venues should not be designed to create a 'clinical' feel or put barriers up between people.

Members of the LGBT+ community indicated that there needs to be much greater transparency surrounding assessment meetings than at present. Applicants should be able to record the meeting, sign off on the assessor's notes and be given a copy to take away. This meant that if it went to appeal people have a mutually agreed record of what was said.

Deadlines and timelines

More time needs to be allowed for the application process. Some conditions have symptoms like fatiguing and brain fog, which means that people are unable to apply or be interviewed over the phone and written applications can take time to complete.

People shouldn't have to wait any longer than one calendar month for a decision after their first application. Some members of the LGBT+ community indicated that they wouldn't mind if a review meeting was brought forward, as long as they would continue to receive their entitlements for the original award period.

Financial support

People indicated that provisional payments should be made from the moment an application is received, and that payments should continue to be made until an appeal process is thoroughly exhausted.

Appeals

Members of the LGBT+ community agreed that the appeals process needs to be quicker than at present. It is also important that if someone has to appeal there is full disclosure by the new agency as to why a claim has been unsuccessful and when payments will be stopped.

Some focus group participants proposed that people should be able to appeal two or even three times.

There is a need for medical support, such as doctors and consultants, where required. There also needs to be access to third sector support organisations in the appeal process, and the Scottish Government needs to fund those organisations to be able to deliver this.

Focus group participants felt very strongly that, particularly in rural or remote areas, motability vehicles should not be removed until the appeal process is thoroughly exhausted.

Support to return to work

Members of the LGBT+ community proposed that a supportive, phased return to work scheme be introduced as part of the new system. There should be a trial period if someone's health is improving, to enable them to take on more volunteering or paid work and transition off social security, without being forced to push their limits or losing entitlements if it doesn't immediately work out.

> *"You need to have an advocate. It could be a carer, family member or friend. Someone who has empathy, knows your condition and can say that they are entitled to and this is how we can help and not hinder you"*

> *"Someone can miss out on a benefit because they are nervous or not good at expressing themselves or not feeling well"*

> *"If it is localities they know the area, they know issues with transport, what transport options there are. Specialists on that panel have that understanding and empathise with what special requirements you may need."*

> *"Assess the assessors – we pay taxes and they should give excellent customer service."*

> *"A lot of people don't like to write, a lot of people don't have access to computers, not everybody knows the right words. The form should be simple, no abbreviations, clear, concise. The common man should be able to understand it"*

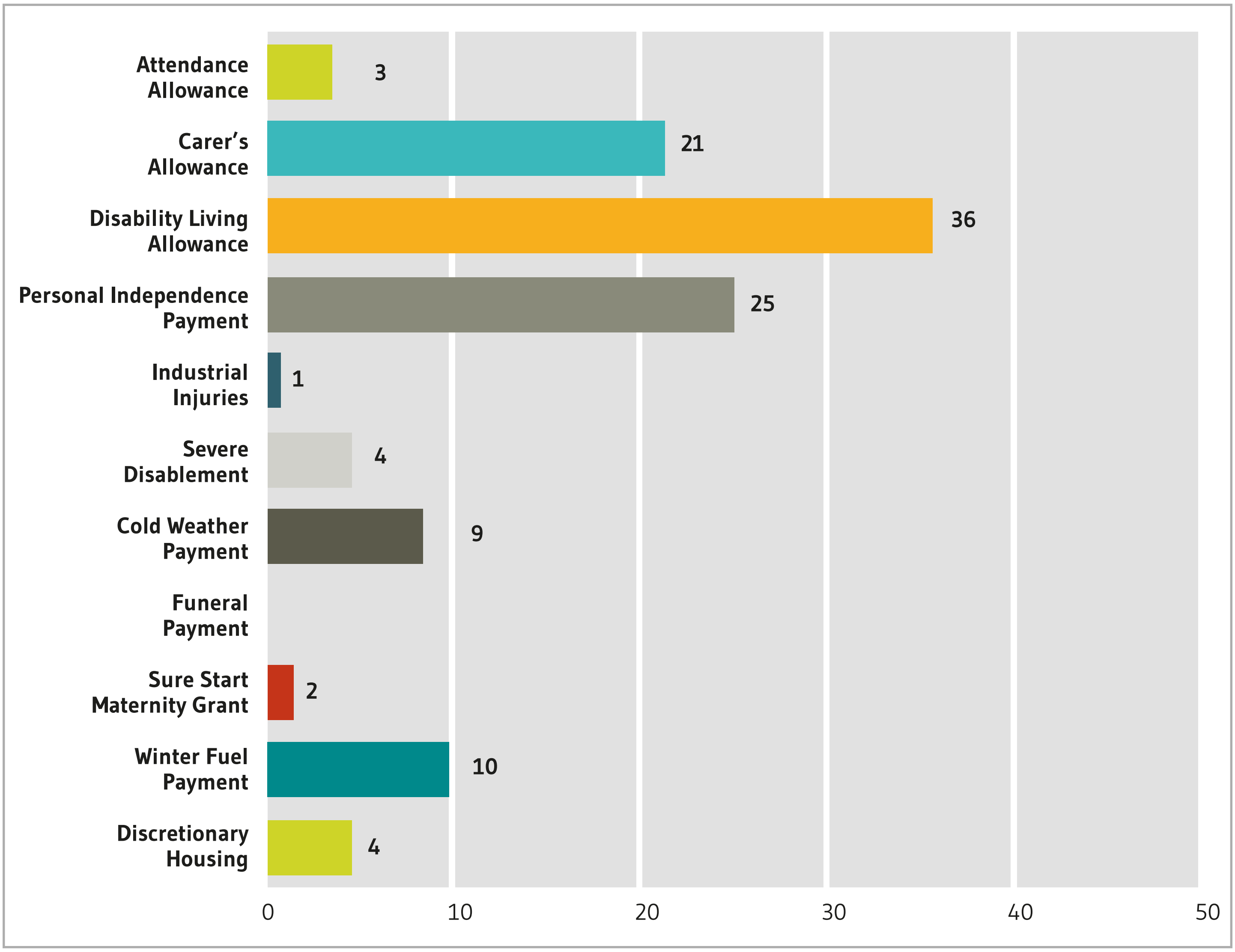
> *"This happens at the moment, if you do something wrong then you are sanctioned straight away, you get not a penny and then you've got rent to pay. So what do you do? You could be out on the doorstep"*

> *"He went for the assessment and they took the car off him there and so how was he mean to get home?"*

People living in rural or remote Scotland

Survey respondents

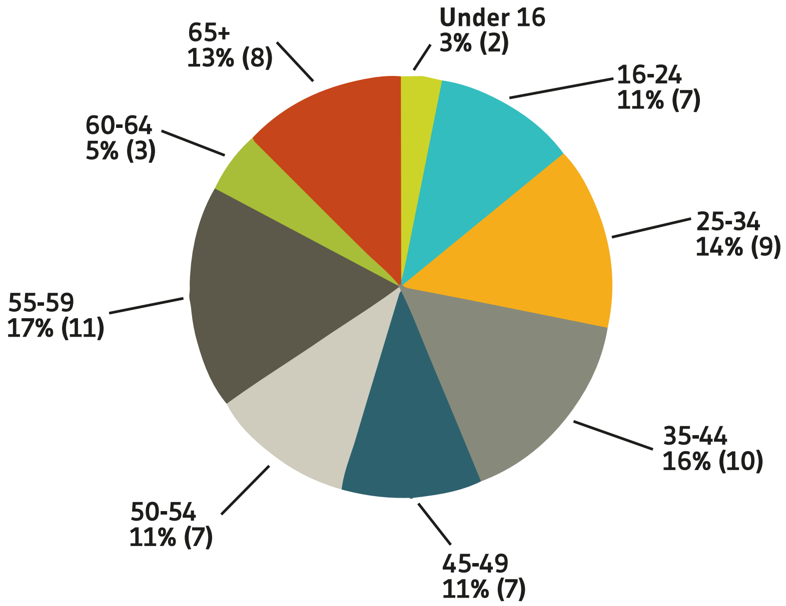
Experience of social security



Self-identification

Answer Choices	Responses	
Rural/remote dweller	100%	64
Homelessness experience	8%	5
Sensory impairment/multiple conditions	34%	22
Mental health issues experience	38%	24
BME community member	3%	2
LGBT+ community member	5%	3
Learning difficulty	3%	2
Unpaid carer	3%	2
Long term condition	2%	1
Physical disability	5%	3
Survivor of trauma/abuse	2%	1
Total Respondents: 64		

Age and gender identity



61 per cent female

36 per cent male

3 per cent other

Focus group participants

Six focus groups with 51 people were held with people who identify as living in rural or remote Scotland. Three groups were held in Inverness in partnership with HUG Action for Mental Health, two groups were held in Dumfries and Galloway in partnership with Dumfries and Galloway LGBT Plus and one group was held in Boat of Garten in partnership with the SDEF Access Panel of Badenoch and Strathspey.

There were seven participants in the SDEF Access Panel focus group; six women and one man. Participants were aged 55-59 and 65+. They had experience of DLA, PIP, Carer's Allowance, Severe Disablement Allowance, Cold Weather Payment and Winter Fuel Payment. As well as living in rural or remote Scotland, these participants self-identified as having lived experience of disability and mental health issues. Demographic data for participants in the Dumfries, Stranraer and Inverness focus groups can be found in the previous chapters on people with lived experience of mental health issues and members of the LGBT+ community.

Views

For additional views of people who live in rural or remote Scotland, please refer to the previous chapters on people with lived experience of mental health issues and members of the LGBT+ community.

Applications and reviews

As with other seldom heard groups, people living in rural or remote Scotland believed that if an applicant has a long term condition and a medical report supported by their GP then an assessment meeting shouldn't be necessary. They also believed that for people with long term conditions the list of eligibility criteria could be reduced and there could be a shorter assessment. People with degenerative conditions should be automatically awarded social security.

People living in rural or remote Scotland indicated that there could be individuals with a long term condition that could become manageable and allow them to return to work. In this case, they would be suitable for a review, however their doctor could supply a letter saying they had improved and won't require a reassessment meeting.

Eligibility

Participants believed that training is essential for whoever is conducting the assessments. Assessors must be able to retain the knowledge and understanding that they are dealing with real people. Skills, experience and knowledge in the condition of the person being assessed would be good. Voluntary organisations such as the RNIB could be valuable assets in providing training for new assessors.

Participants also believed that a doctor or consultant who is familiar with the applicant's condition should be involved and that the decision-making panel have a good knowledge of the applicant's condition and a flexible approach.

Information and communications

Participants thought that the new system should be more accessible and open about the payments that people may be entitled to. They proposed creating 'Information Officers' who would work in the community to provide information on what people might be entitled to. There should also be an option to indicate a preferred communication method on application forms.

Culture, behaviour, attitudes and skills

Participants in rural or remote Scotland felt strongly that there needs to be a significant culture change regarding the attitudes and standard of conduct of assessors in the new system, and that compassion is essential to this. A person centred approach to the assessment process and claimants is needed.

Independence and accountability

Participants strongly agreed that the new social security assessment process should not be delivered by a private company and that it should be held to account. They suggested the creation of a something similar to the Care Quality Commission that could act as an independent oversight body of the new social security agency. People also suggested that evaluation forms be given to applicants to provide feedback how the assessor was, any issues with their application, etc. which could be sent into an independent oversight body.

Application forms

People noted that the application form needs to be shortened, written in plain language and contain less 'tick box' questions.

Personal support, independent advocacy and advice

Focus group participants particularly mentioned the Citizens Advice Bureaux as an extremely important resource for people in rural or remote Scotland. However they also noted that it needs much better resourcing if people are going to be able to fully access it in future. People also noted that during the assessment process there needs to be independent, impartial support provided to any applicant that requires it.

Assessment meetings

If an assessment meeting is required, it should be conducted in a setting, including at home, and time that suits the applicant. The duration of assessment meetings should be tailored to what individual applicants can cope with – one participant spoke about a 4-hour long interview, which was excessive.

Rural or remote participants all agreed that if it is not possible to create social security venues in local areas then assessment meetings could be conducted in other local settings, including health centres, community halls, etc. Support for travel, especially in rural or remote areas, is essential. Claimants should be able to see a copy of the form and notes at the end of an assessment meeting, sign it to confirm that they agree with what has been written, and take a copy away with them.

Deadlines and timelines

People in rural or remote Scotland recommended that a longer time period be given to help people complete the application form. People should be informed about a decision no longer than a month after their application has been submitted.

Financial support

People in rural or remote Scotland agree that if an application has to go through an appeal then entitlements should not be cut off until the whole process is exhausted.

Appeals

People agree that people need to be told very clearly why their application was unsuccessful and that the appeal process should be quick.

> *"What kind of training should they have? Humanity, manners, communication skills, tact"*

> *"As [someone who is] visually impaired I would like someone who knows about visual impairment or would be able to provide support in filling out the form"*

> *"it took so long because I found it hard to concentrate."*

> *"Needs to be someone who understands the condition, has training in understanding, disability training, disability awareness"*

> *"The interview should only be supplementary to the information provided on the form"*

> *"Decisions being based on what people require rather than externally set targets such as money"*

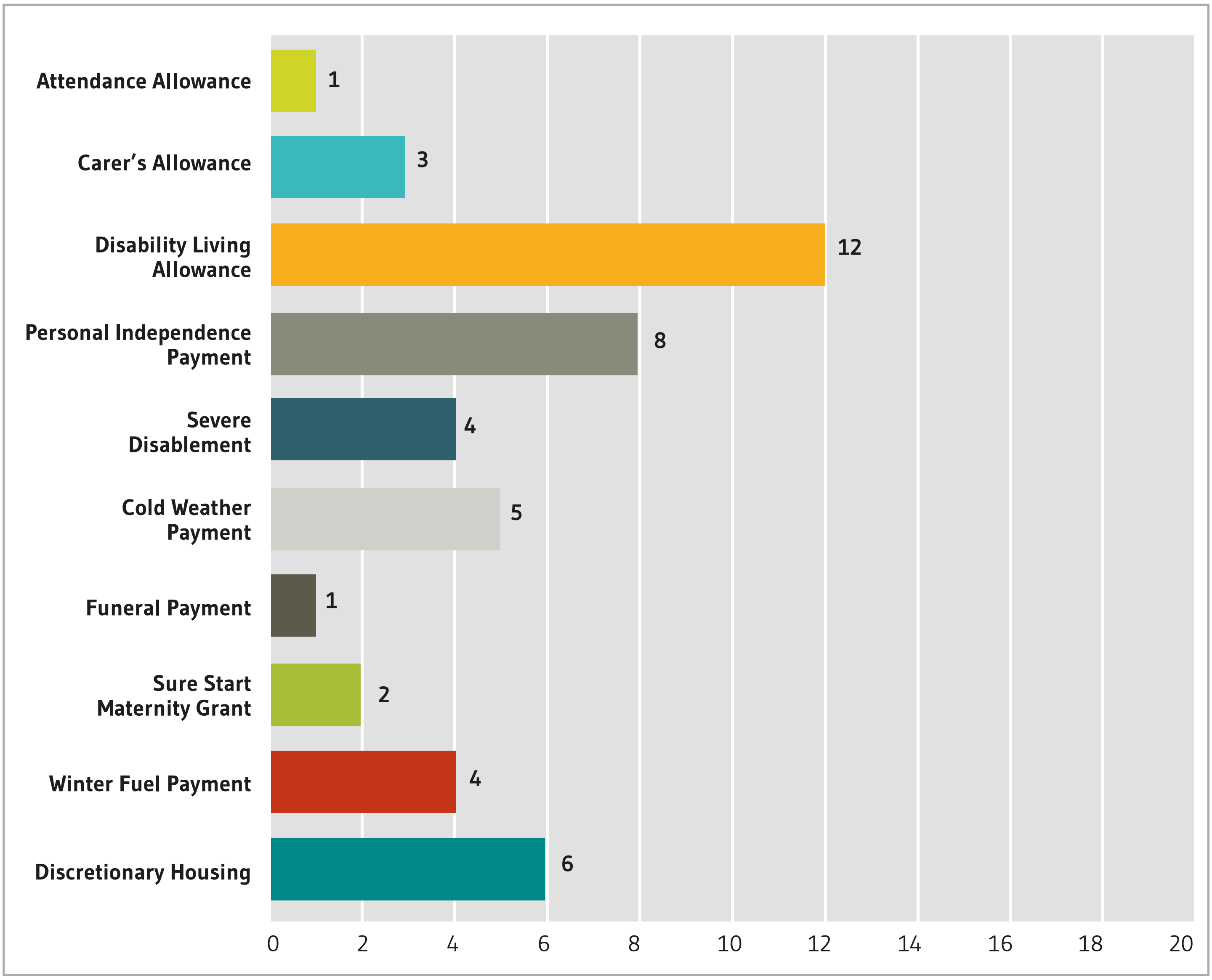
> *"If you are expected to travel then they need to take into account that it is not easy to do so in rural communities"*

> *"Onus on the [assessment] body so that there is a limited time [till your appeal date] and cut off time for them to complete the process"*

People with experience of homelessness

Survey respondents

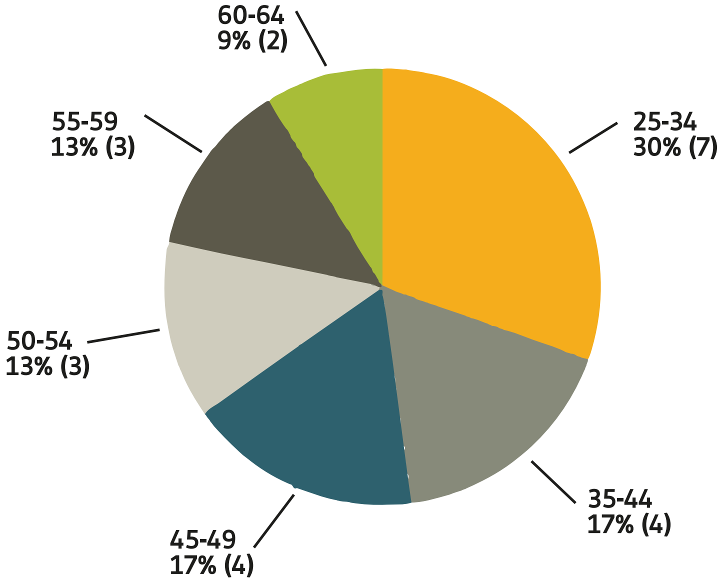
Experience of social security



Self-identification

Answer Choices	**Responses**	
Rural/remote dweller	22%	5
Homelessness experience	100%	23
Sensory impairment/multiple conditions	30%	7
Mental health issues experience	61%	14
BME community member	13%	3
LGBT+ community member	30%	7
Long term condition	4%	1
Physical disability	4%	1
Care experienced	4%	1
Total Respondents: 23		

Age and gender identity



57 per cent female

39 per cent male

4 per cent trans

Focus group participants

Four people participated in a focus group for people with experience of homelessness in partnership with Glasgow Homelessness Network. Participants had experience of DLA, Cold Weather Payment, Winter Fuel Payment, ESA and JSA. Participants self-identified as people with lived experience of homelessness; lived experience of mental health issues; and disabled. One woman and three men participated, in the 35-44, 45-49 and 55-59 age groups.

Views

Applications and reviews

Participants agreed that some form of assessment was required but the way in which this process is carried out is crucial. Some long term conditions should not require an assessment and the amount of time between reassessments should depend on the particular condition. There should also be an option to complete an assessment over the phone. Some focus group members also felt that there should be a clearer process that allows people to pro-actively request a review later down the line where there has been a change in their condition or circumstances.

Culture, behaviour, attitudes and skills

Participants identified a range of characteristics which should be demonstrated by all professionals involved in the process – training in emotional intelligence and active listening; an understanding of the impact of mental health, not just physical impairments; someone that knows you (e.g. your GP) should be involved; collaboratively working with the NHS.

Participants also noted that combative language was often used about the current system and felt that this was a sad reflection on how much of a struggle the process can be.

Any new assessment process should recognise that everyone has a different learning style. This should allow for the assessment to make provision for ‘feelings questions’ as well as more visual elements. It should also be tailored to enable people to give their side of the story without feeling under pressure to “fit” responses in to the assessor’s way of thinking and recording information.

People were keen to stress that there should be scope to ensure that the new social security agency runs along a similar model used by the Children's Panel, with greater level of volunteer involvement. This would have the potential to make the process more independent and impartial. They also expressed the need for much closer alignment between the social security agency and other services involved in people's lives, like health and social care. Joining up key messages coming from statutory services could have the impact of addressing confusion about the social security system's expectations of people who use it.

Information and communications

The group noted that a balance should be struck about the amount of notice that people should be given ahead of their assessment. Assessments shouldn't just be "dropped on people" at short notice, but how the notification letter is worded is also very important – sensitive wording should recognise that people will be stressed out on receipt of the letter. Information should be supplied with the notification of an assessment that helps people to be "tooled up" with everything they need to know about what will happen. Mechanisms should also be in place to allow people to ask questions before an assessment. This could also allow for assessments to be a trigger for offering other forms of advice, support and signposting to community resources that can help the person who is attending the assessment – defined by their individual needs.

Personal support, independent advocacy and advice

Participants said that there should be provision for someone (family member, partner, friend, or independent advocate) who can be there in the room with you as a practical support as part of the new system. Advocacy can be helpful because lots of people don't understand the language, procedures and situation they are in and this can result in people being unable to articulate their circumstances.

Assessment meetings

The use of community venues should be considered for future assessments, rather than city centre offices. Room layout is also an important factor – and should be set up in a way that is not adversarial and puts people at ease.

Deadlines and timelines

Participants said that there should be a short, required timescale for decision making – as waiting for a decision can have a significant impact on people's mental health and wellbeing. Required timescales should also apply to appeals.

> *"Adequately fund a system where people can get full reports from their own medical support staff for the assessment process."*

> *"Having someone with no medical experience question and judge your illnesses is detrimental to recovery/health."*

> *"Be more transparent and fair – current system depends on the 'skill' of the person applying rather than the needs of the individual."*

> *"The person should be notified it will be happening by letter if necessary but an actual person should call to confirm the person understands what's happening."*

> *"A person's genuine medical problems and needs must be taken properly into account. This is not possible in a tick-box, one-size-fits-all assessment. Cumulative effects of multiple conditions need to be taken into consideration."*

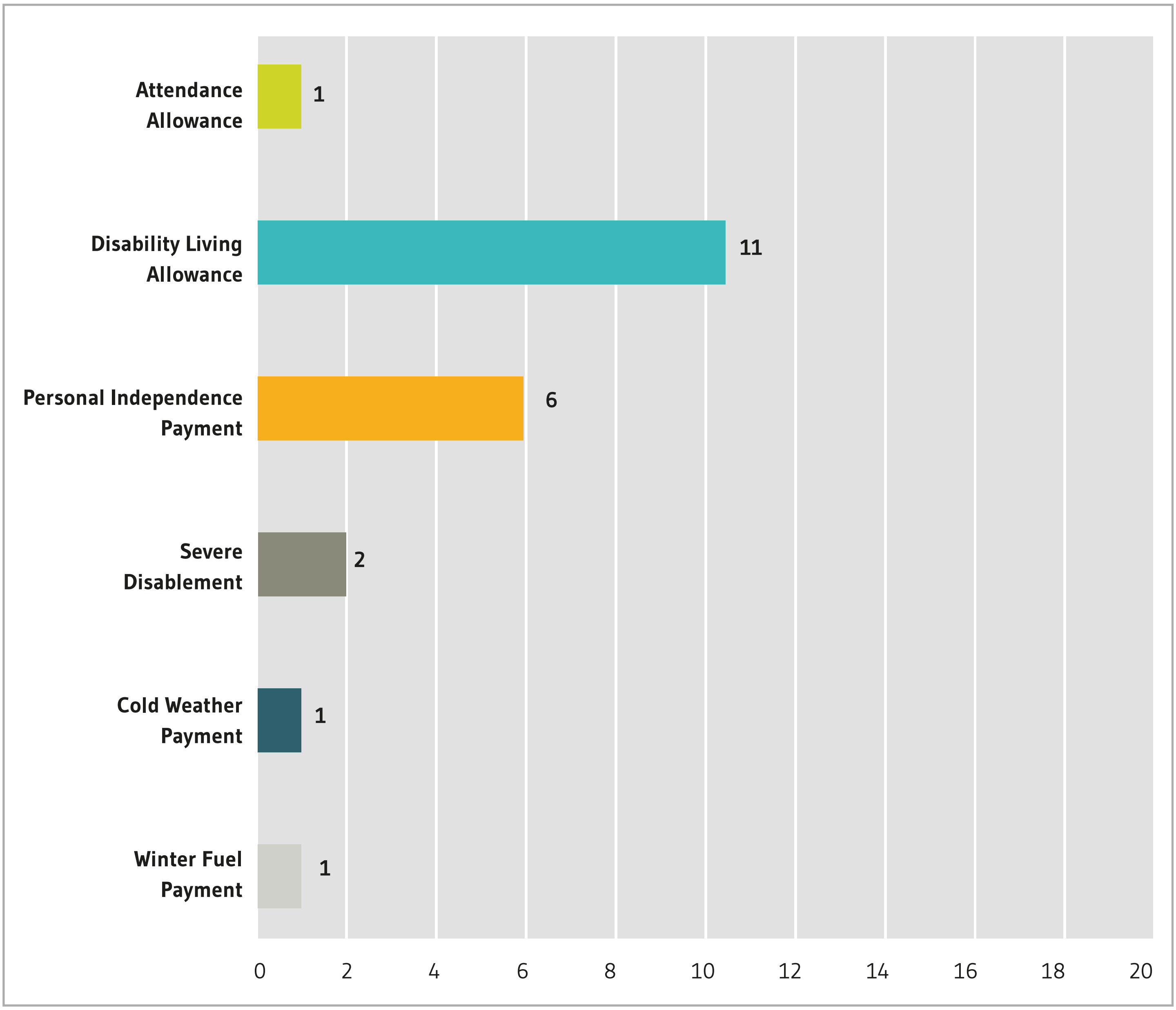
> *"Respect has to be given to the claimant for their lived experience of their disability or condition. It is not easy to live with any disability and this is not acknowledged in the current system. More weight should be given to the word of the claimant."*

> *"Person needs to be made aware of what happens next and a timescale. This would also be an excellent opportunity for a helpline."*

People with learning difficulties

Survey respondents

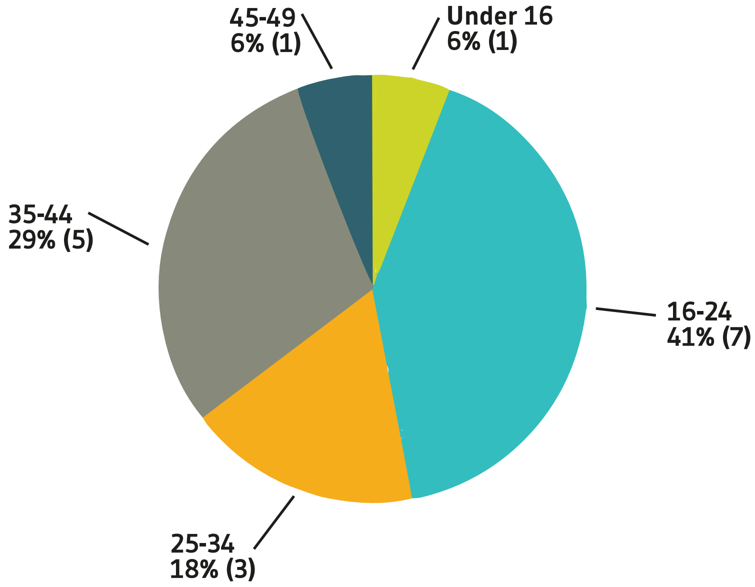
Experience of social security



Self-identification

Answer Choices	Responses	
Rural/remote dweller	12%	2
Sensory impairment/multiple conditions	12%	2
LGBT+ community member	6%	1
Learning difficulty	100%	17
Long term condition	6%	1
Physical disability	12%	2
Total Respondents: 17		

Age and gender identity



35 per cent female

59 per cent male

6 per cent other

Focus group participants

Six people participated in a focus group for people with learning difficulties organised in partnership with People First (Scotland). Participants had experience of DLA, PIP, Cold Weather Payment, Winter Fuel Payments, Carer's Allowance, Attendance Allowance, Severe Disablement Allowance, Discretionary Housing Payments, Income Support and ESA. Participants also self-identified as disabled, having lived experience of mental health issues, lived experience of homelessness and as a single parent. Three women and three men participated, in the 35-44, 45-49 and 50-54 age groups.

Views

Applications

There were mixed views on the existence of an assessment process. Some participants felt that there should be an assessment process but not if you have a long term condition that is unlikely to change over time. Others felt that there should not be an assessment and that GPs should have a greater role in the evidence gathering process.

Eligibility

People with learning difficulties felt that someone who knows them and that they've met before would be much better at making a decision and judgement about their needs. This could be more than one person in some circumstances. Participants were clear, however, that this should not be an IT or computer-led process but about contact between people.

Information and communications

The Scottish Social Security Agency must help explain what is going to happen and what is expected in formats that are accessible to people with learning difficulties, including in easy read. People also said that they would like to receive information on the type of support they can access to help them with completing forms as an accompaniment to the form.

People with learning disabilities should be able to receive a straightforward, easy read map and picture of the building they are being asked to attend. This would enable them to find the venue and support with travel arrangements.

Participants said that following an assessment they needed information on what would happen next and when. They should also receive easy read information on their potential options following an assessment. This should all be produced in easy read formats.

Independent advocacy

People highlighted the significant role independent advocacy can play in supporting people with learning difficulties through social security processes. They can help to interpret the questions that are being asked so that a more accurate answer is given.

Culture, behaviour, attitude and skills

The focus group suggested that assessors should smile, look relaxed, listen openly and have a good attitude to people with a learning difficulty. This should involve talking directly to the person rather than sitting at a computer typing.

Assessment meetings

Participants said that there needs to be enough notice given so that they can make sure support workers and advocates can be with them on the day or childcare is arranged. This should be flexible enough to allow for rearranging of appointments if the time and date doesn't suit or an unplanned event occurs.

Participants felt that there should be greater responsibility on the assessor to gather information about the person before the face to face assessment meeting. This could include asking other people about them, tailoring questions to make sure they are relevant and knowing what people's background history is.

People with learning difficulties said that they want to be involved in and know what is being written about them and co-produce what is submitted to the decision makers.

> *"An assessment body who is totally independent and without prejudice and is not working from a flow chart or indeed for profit"*

> *"An advocate who is able to process the questions and help with the processing of answers for people with learning disabilities should be present."*

> *"Longer appointment times, accessible areas with staff who understand the needs of vulnerable people."*

> *"People should be fully informed as to the nature and purpose of the assessment, likely outcomes and effect these may have on a person."*

> *"Practice in a way that is informed by research and other evidence."*

> *"The whole person and their situation should be looked at. People do not live in a vacuum."*

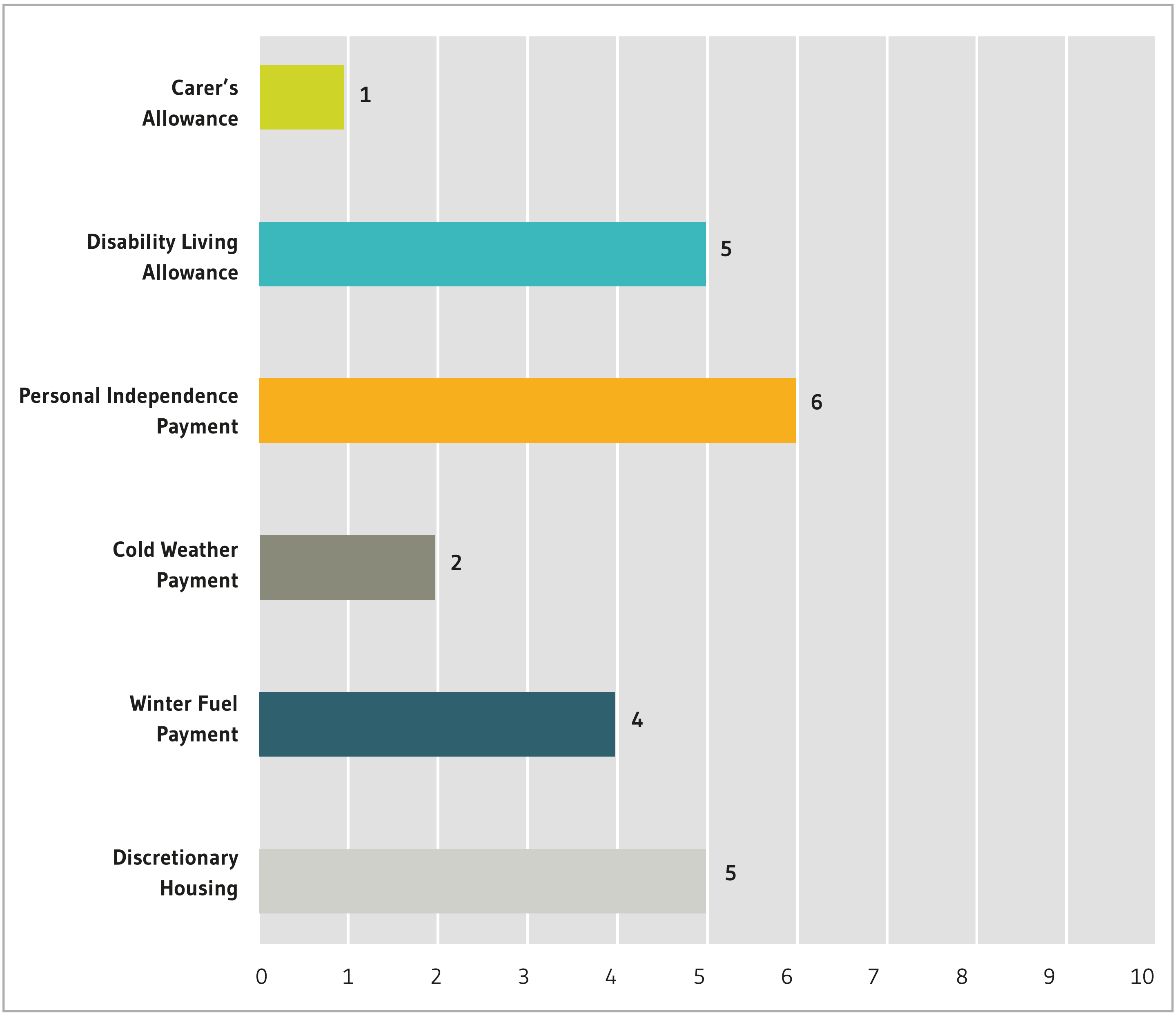
> *"Ensure any 'vulnerable' person always has support with them during assessments."*

> *"Evaluate the 'experience' of the person being assessed."*

Members of the BME community

Survey respondents

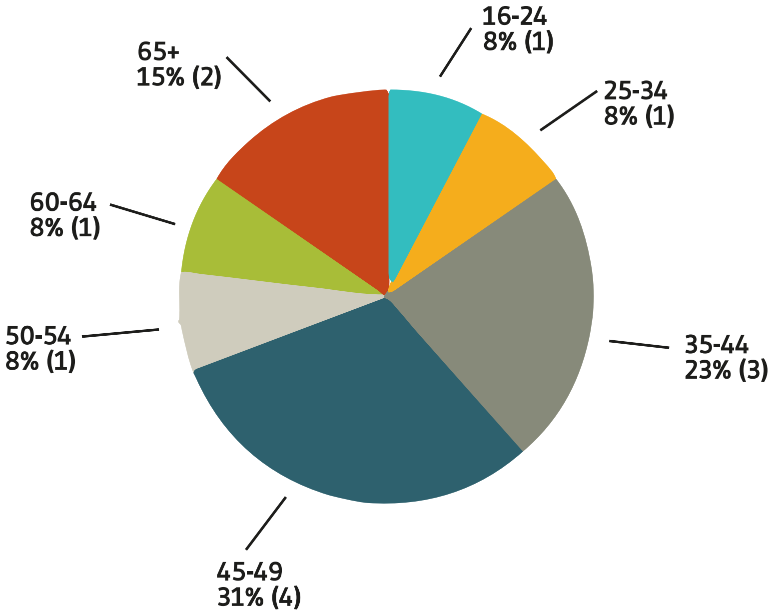
Experience of social security



Self-identification

Answer Choices	Responses	
Rural/remote dweller	15%	2
Asylum seeker/refugee	8%	1
Homelessness experience	23%	3
Sensory impairment/multiple conditions	38%	5
Mental health issues experience	62%	8
BME community member	100%	13
Long term condition	8%	1
Total Respondents: 13		

Age and gender identity



54 per cent female

46 per cent male

Focus group participants

Three members of the BME community participated in a focus group that the ALLIANCE organised in Glasgow with support from the Coalition for Racial Equality and Rights (CRER), RNIB Scotland and the Poverty Alliance. Participants had experience of Carer's Allowance, Attendance Allowance, PIP and Winter Fuel Payments. Participants also self-identified as members of the refugee/asylum seeking community, having lived experience of mental health issues and as disabled. Two women and one man participated, in the 35-44, 50-45 and 65+ age groups.

Views

Lifetime assessment

As with most consultation participants, members of the BME community believed that an assessment process of some kind is necessary to ensure there is fair accountability and entitlements are directed to the right people. Assessments should also be made on a one-time only basis for people who are diagnosed with conditions that are not going to change. If reviews are required, these should be prompted by the claimant and based on the medical evidence provided by people that know them. Reviews should also enable claimants to seek and aquire more, not just less, entitlements.

Applications via form only

Members of the BME community agreed that applications could frequently be made using only an application form, without the need for an additional interview. When supporting information is required this should come from those who know the applicant, whether medical or otherwise.

Eligibility

People from the BME community thought that assessors must be impartial, not work for a private company, and have medical knowledge and knowledge of the claimant's condition(s). The claimant should inform assessors who to consult concerning their application and for them a consultant is preferable to a GP. Others who could provide supporting information include social workers, housing and mental health professionals.

Deadlines and timelines

Members of the BME community believed that applications from those with terminal illnesses should be fast tracked so they get prompt access to the support they need.

Participants indicated that applications should be processed quickly: ideally within two weeks, and no more than a month. They thought that the four-week deadline for appeals to be lodged needs to be extended to give people more time to source supporting information and review and complete the form, which in its present format is too long.

Information and communications

Participants believed that there needs to be an education and awareness campaign for members of the BME community because people may not be claiming for everything they are entitled to.

Participants indicated that the assessment process can be particularly stressful for some members of the BME community, for example those from Africa, who may not understand some questions or how to correctly answer them. There needs to be greater awareness that English may be a second language for some applicants and access to free translation if required. Information, guidance and forms should be written clearly and accessibly, and made available in a range of different languages.

Claimants should be kept informed of progress throughout the assessment and appeal process.

Personal support, independent advocacy and advice

Specialist support to complete application and appeal forms should be available, and people should be able to have a support person present at assessment meetings. Trained peer support and independent advocacy were also mentioned.

Application forms

People should have a choice as to the format of the application form. Many people from the BME community don’t necessarily have access to the internet or experience of online form-filling.

Financial support

Some people indicated that financial support should be available while applications are being processed.

Culture, behaviour, attitudes and skills

People from the BME community need to feel that the system is not against them, which can make them feel tense and stressed. Assessors shouldn’t make claimants feel like the ‘enemy’ or take an approach that makes people feel threatened.

The ideal assessor would be friendly, create a good rapport with the client and have good listening skills. In fact this kind of attitude should extend across everybody in the agency, from the assessor to the receptionist. Assessors also needs to be aware of, and sensitive to, cultural differences. Training is seen as key to ensure an equalities and person centred approach.

Assessment meetings

If an assessment meeting is required, claimants should have a choice as to whether it is face-to-face or over the telephone. Participants indicated that at present there was little or no information that indicated if there was the option to have a home assessment, which should be made available in the future. The group agreed that if there has to be a face-to-face assessment meeting at an agency locale, then it should be at a place close to home.

Members of the BME community believed that claimants should be able to choose the gender of the assessor if at all possible.

Participants thought that if there are notes taken at the meeting then the claimant should be given a copy of them straight away. They also thought that people should have the option to read over the notes and sign to agree that it is an accurate record of what was said at the meeting. The option to audio record assessment meetings should be available if that is more suited to the individual. At the end of the interview, applicants should be given a document with information about the process: next steps, how and when a decision wil be made, and what to do if the application is rejected.

Appeals

The appeals process needs to be streamlined and, if an application is unsuccessful, the notification letter should let people know why, with clear information about the basis upon which a decision was reached and a breakdown of their scores.

Step-by-step guidelines about the appeal process should be provided, including information about where to send it, who makes a decision, and so on.

> *"the reason they removed lifetime support was to ensure that people will get the right level of support. But if you have a long term condition that is not going to change then repurposing reassessment is a game changer in terms of the time it takes to go through that"*

> *"it's not the job title, it's the medical professional with the most knowledge about you and your condition"*

> *"I think the role of third sector organisations could be useful if the person is happy to have them there. I would have never gone for PIP if I hadn't had the support of Deaf Blind Scotland"*

> *"there is no place for a private company, they are trying to make money. It should not involve anybody who is involved in making a profit"*

> *"I think you need to choose because you are going to meet a complete stranger. Daughter was so nervous about going. There was already information and evidence which they have access to and it felt like we were going to a court case to be judged, which is what happened"*

> *"with my daughter, [who is] a young girl, and the way she responds to men and I see it when we go to the hospital and how she deals with female and male staff. When she is with female staff she is more comfortable"*

> *"more transparency on why you were rejected, more help on how to carry out the appeal, independent advice and support on the form and appeal meeting"*

Members of the refugee/asylum seeking community

Survey respondent

The one respondent who indicated they belong to the refugee/asylum seeking community also indicated they have lived experience of mental health problems and are a member of the BME community. They indicated they are a male, aged 35-44 years, with experience of Discretionary Housing Payments. They believe there should be an assessment process. The person making a decision about who qualifies should be experienced and have qualifications for the job, and financial and personal support should be made available to applicants.

Focus group participants

One focus group for members of the refugee/asylum seeking community was organised in partnership Saheliya. Around thirty people took part and we gathered demographic data for sixteen. These participants all identified as women and were aged 16-59. They indicated direct experience of PIP, Attendance Allowance, Sure Start Maternity Grant and Income Support. Participants also self-identified as having lived experience of seeking asylum or being a refugee, being from the BME community, lived experience of homelessness and living in rural or remote Scotland.

Views

Lifetime assessments

During the focus group, the participants noted that there were some people who should not require an assessment for eligibility, with particular reference to people with life limiting illnesses, but they also recognised that there was an inequity in what was defined as "a disability" with some expressing concern about physical disabilities not being prioritised.

Eligibility

The focus group highlighted the important role that case workers, who are often well known to asylum seekers and refugees, could play in giving well rounded information on individuals and their backgrounds/experiences.

Personal support

The focus group emphasised the importance of a range of help and support during the assessment process including language support, with participants putting particular emphasis on language support from independent organisations. Translation and support workers should also be available to attend assessments with people.

Culture, behaviour, attitudes and skills

Some participants suggested that training for assessors must emphasise the importance of understanding sensitive issues including domestic violence and experience of conflict.

Many of the participants expressed concern about the relationship between the benefits system and employment outcomes. They noted that there were positive benefits to being in work – but support to stay in work was not always well publicised (e.g. working tax credits) and many people who want to work are unable to because they have no childcare options.

Information and communication

Participants identified that many people seeking asylum were not made aware of their entitlements or otherwise after receiving their papers. They recommended that the Scottish Government closely consider how the new social security system works with the Home Office to give both advice and access to short term loans. Accessible information should be available in a variety of languages that recognises the range of people who are new to Scotland.

The process following an assessment was seen as not always being a clear one – people should be properly informed of their rights and entitlements after an assessment. Participants also said that closer relationships also need to be developed between the social security system and training/employability programmes which recognise the characteristics of asylum seekers and refugees.

Assessment meetings

Participants noted that choice was needed over the venue of any assessment, expressing a fear of being "judged" if an assessor came to your house. Some participants noted a lack of diversity in the people who were carrying out assessments. The focus group also welcomed the idea the individual may be able to specify the gender of the assessor.

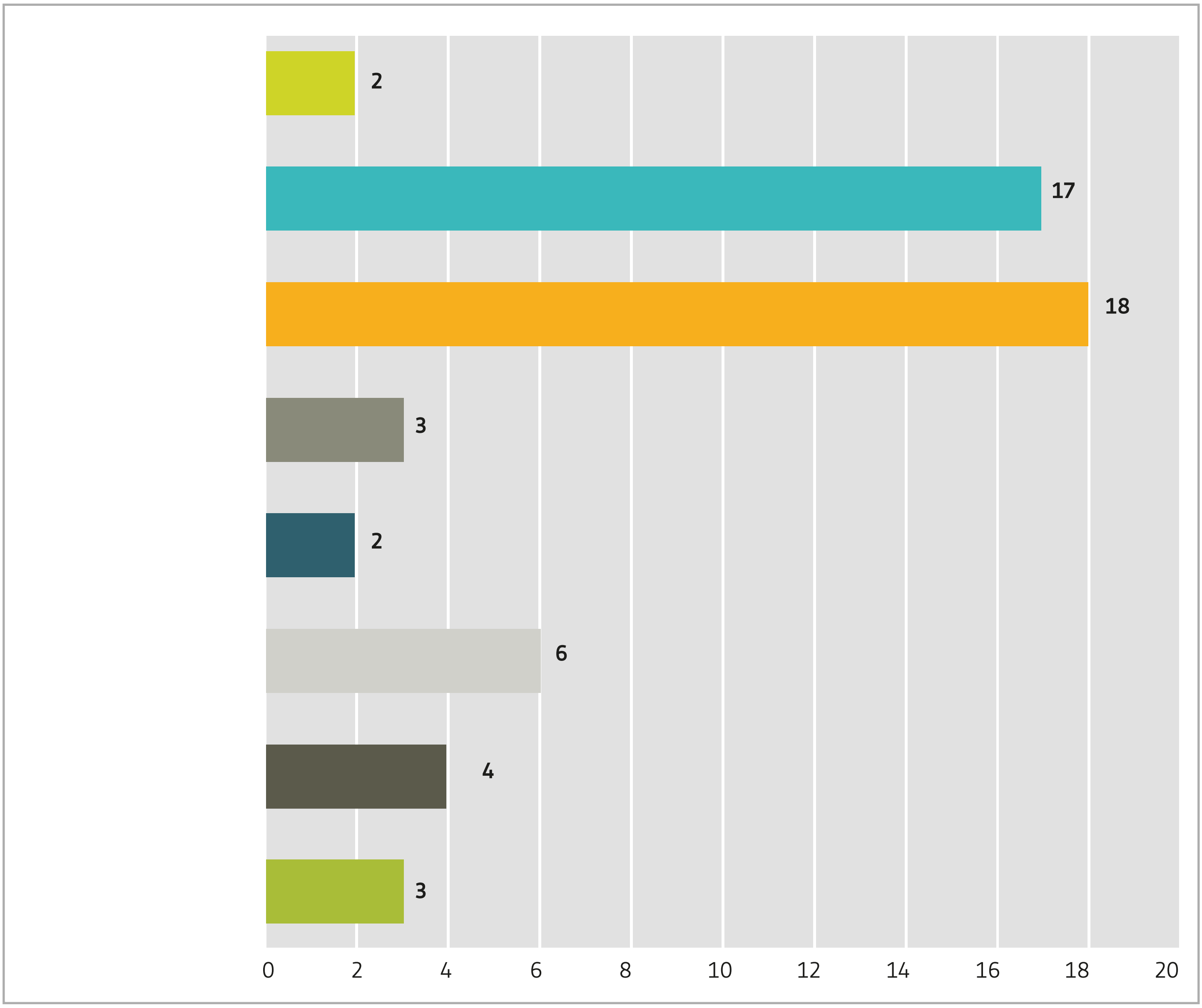
Deadlines and timelines

Some expressed concern about the length of time an assessment process can take – and how they can get crisis support in the meantime.

Unpaid carers

Survey respondents

Experience of social security

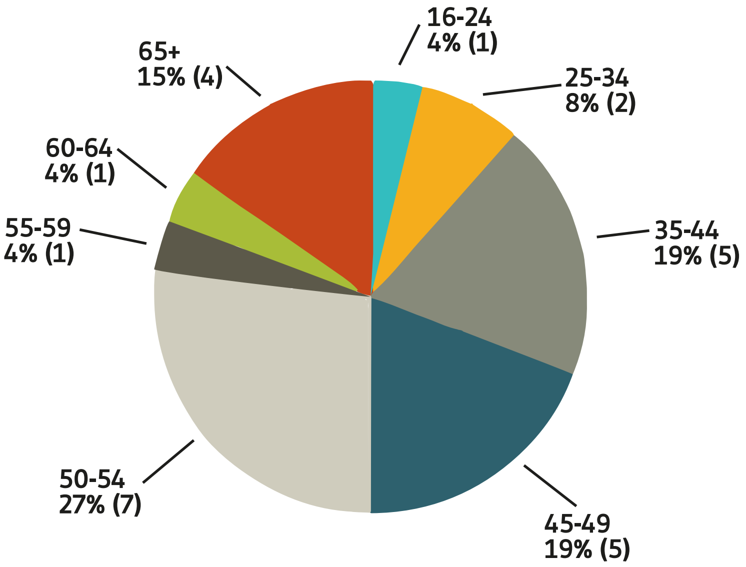


We believe that some unpaid carers will have completed the survey based on their experience of the entitlements of those they care for (e.g. DLA) as well as their own entitlements (e.g. Carer's Allowance).

Self-identification

Answer Choices	Responses	
Rural/remote dweller	8%	2
Sensory impairment/multiple conditions	8%	2
Mental health issues experience	8%	2
Unpaid carer	100%	26
Physical disability	8%	2
Total Respondents: 26		

Age and gender identity



77 per cent female

23 per cent male

Focus group participants

One focus group for six unpaid carers was organised in partnership with Carers Trust Scotland. As well as Carer's Allowance, participants had experience of ESA, Cold Weather and Winter Fuel Payments, PIP, DLA and Attendance Allowance. Amongst the group, there were participants who also self-identified as LGBT+, living in rural or remote Scotland, as disabled and having lived experience of mental health issues. Five women and one man took part, in the 25-34, 45-49, 60-64 and 65+ age groups.

Views

Lifetime assessments and reviews

As with participants overall, most unpaid carers believed there needs to be some sort of assessment process to ensure there is clear accountability for public funds and entitlements are awarded to the right people. However, members of the focus group indicated that people on the emergency transplant list should be exempt from any assessment

Unpaid carers also supported awarding automatic, lifetime entitlements to people with terminal or degenerative conditions like MND and Parkinson's, as well as learning difficulties. The current system was criticised for making so-called 'indefinite awards' but then requiring people to go through a review/reassessment every five years.

There needs to be flexibility around the time in between reviews/reassessments. Unpaid carers also believed that in some cases it would be helpful to be able to apply for a review to identify if a person's requirements have increased, but they should be able to enter into this without the fear of losing the entitlements that they already have.

Application via form only

As with other seldom heard groups, unpaid carers believed that, in some circumstances, applications could be made with a form only, plus supporting (medical) information if required, without the need for an additional interview. If a doctor or nurse has deemed someone unfit to work, then that information should be enough on which to base a decision.

Eligibility

Unpaid carers indicated that the people involved in decision-making need to be unbiased and impartial. In some cases it might only require one assessor to sign off on a decision, whereas in other more contentious cases it might require a panel.

Where medical information is required, health professionals that are known to carers/the person they care for should be involved in decision-making and information provision. In some cases this could be a GP, in others a specialist – it should be up to the claimant to decide.

Focus group participants noted that, in previous years, health visitors would manage a case load of people living with long term conditions and conduct reviews/visits. They felt that this could be an appropriate person to involve in the assessment process, given their ability to build up a detailed knowledge of a person's condition(s) and establish a relationship with them over a period of time.

Information and communications

Unpaid carers believed the new Scottish system should be introduced with a public information campaign. There is a need to dispel the myths that surround social security. For example, some people associate 'social security' with poverty, and don't necessarily realise they may have entitlements. Older carers may be reluctant to claim payments to which they are entitled, due to a desire for 'self-sufficiency' and because social security is overly associated with 'charity'. Being pro-actively approached with information about social security, either by letter or in person, would help address unpaid carers' concerns and make them feel they are legitimately entitled.

Better information is required to make sure everyone is aware of what they are entitled to: focus group participants said they know some unpaid carers who don't apply for entitlements because they believe it will be deducted from other payments they receive and/or the entitlements of those they care for.

Improvements are also needed to keep people fully informed throughout the process.

Personal support

Qualified, informed personal support should be available to help people complete application forms. Unpaid carers also believe there needs to be scope for family, friends or an independent advocate to be in the room with the person who is taking part in an assessment meeting.

Unpaid carers currently have mixed experiences of support from GP practices. Some have found their practices will refuse to help with applications and will only answer appeal letters, however others find their GP more willing to get involved and "support them as a whole person". A more consistent, positive response from health professionals is needed.

Unpaid carers also recommended Community Links Practitioners as support providers through the assessment process

Independent advocacy and advice

Unpaid carers believed people need access to independent advocacy. They noted that people with learning difficulties are often overlooked and that it would be helpful if they could have someone to advocate on their behalf during the social security assessment process.

Some recommended a 'one-stop shop' that people could go along to for advice about social security and also signposting to third sector organisations.

Deadlines and timing

Unpaid carers believed the social security system needs to be quicker at responding rather than waiting until people reach crisis. People also need longer to complete the application form than is the case at the moment and the process for finding out the final result after undertaking an assessment also needs to be faster.

Application forms

In future, application forms need to be made shorter, easier to understand and to complete. There also needs to be scope for the person (or their carer) to ask questions or provide additional information that might not necessarily be captured by the questions on the form.

Culture, behaviour, attitudes and skills

Unpaid carers were clear that there needs to be a change in the language, opinions and attitudes surrounding social security to help challenge and overcome stigma.

At the moment, when a brown envelope arrives in the post it is a cause of instant stress for unpaid carers. The word 'assessment' also looms large in people's minds and puts them off. Rather than an 'assessment', in future it would be better framed as 'a conversation about your circumstances'.

Unpaid carers indicated that if the new Scottish social security agency employs staff that are transferred over from the DWP, cultural and other issues that affect this group, e.g. discontent, must be recognised and addressed. There needs to be a rigorous recruitment process for the new agency's staff to ensure they have the right skills and attitudes. Staff should be required to complete a disclosure process. Staff shouldn't be driven by targets but consider each application on its own merits.

Assessors need to be impartial, experienced, and consider all areas of a person's condition. They need to be able to look at, and give weight to, the long term and must consider the unpaid carers' point of view. Assessors should have good communication (e.g. listening) and interpersonal skills, be able to show compassion and have enough time to listen. They must be able to apply common sense, and the new system must allow them to do so.

As with some other groups, unpaid carers recommend a 'named assessor' is appointed that the claimant and the person who cares for them would have continuity of contact with over all aspects.

Unlike other groups, unpaid carers don't believe that assessors need to be experts in the particular condition(s) that the claimant is diagnosed with. However, they should access this expertise to make an informed decision and should be aware of mental health issues and other so-called 'invisible' conditions. Some unpaid carers believed that assessors could be people who have lived experience of the system.

Assessment meetings

If a meeting is required, unpaid carers believe people should have the choice of whether it is face to face or over the phone. If it is in person, then people should be able to choose the venue, including home-based. There should be greater flexibility in (re)arranging meetings to a time that suits the claimant and the person that cares for them.

Unpaid carers think that people need to be given advance notice of what areas will be covered and questions asked, particularly if the conversation will take place over the phone. Topics and questions must be relevant to the person and the condition they live with. Current questions, like "Can you bend down and lift an empty box?", are completely irrelevant or meaningless for some claimants. It would also be helpful if assessors asked questions and gave prompts like "tell us what it is like on your worst day?" Some people may be determined to present as capable as possible during an assessment meeting, which may count against them in the decision-making process.

While it is important for assessors to facilitate discussions on what a 'bad' day is like, an overly deficits-focused assessment can create a difficult dynamic for the carer and cared for person. The role of an unpaid carer is to provide support, help build confidence and self-esteem, and empower the person they care for to fulfil their potential. However, a deficits-focused assessment runs counter to this if an unpaid carer is asked to list all of the things that the cared for person cannot do whilst in their presence. There should be an option for an additional, separate, carer interview to help people share their in-depth insight into the cared for person's condition and circumstances.

Unpaid carers also noted the importance of visual presentation and cues. Some noted that assessors wearing of lanyards with identification cards creates the impression of an 'authority figure' and serves as a barrier between the assessor and claimant. However, others recognised the need for assessors to identify themselves to claimants, particularly where they may be entering people's homes for assessment meetings.

As with other groups, unpaid carers believed the new assessment process needs to move away from current practices that seem designed to try and work against, rather than support, claimants. Experiences shared included assessment venues deliberately locating water dispensers in order to force people to walk a certain distance to get to them (and make some form of assessment based on that fact), or deliberately dropping objects (such as tissues) on the floor to see if people undertaking or about to undertake an assessment can bend down to pick them up.

Unpaid carers noted that people should be entitled to a copy of the notes and paperwork that is completed during assessment meetings. The assessor and new agency should proactively make people aware of their right to this, rather than simply disclosing it upon request.

> *"It needs to be an unbiased but supportive impartial person"*

> *"If a doctor and a nurse are saying that you are not fit to work then that should be it, there should be no debate about it among assessment staff"*

> *"Some people will need independent support or assistance to navigate the system"*

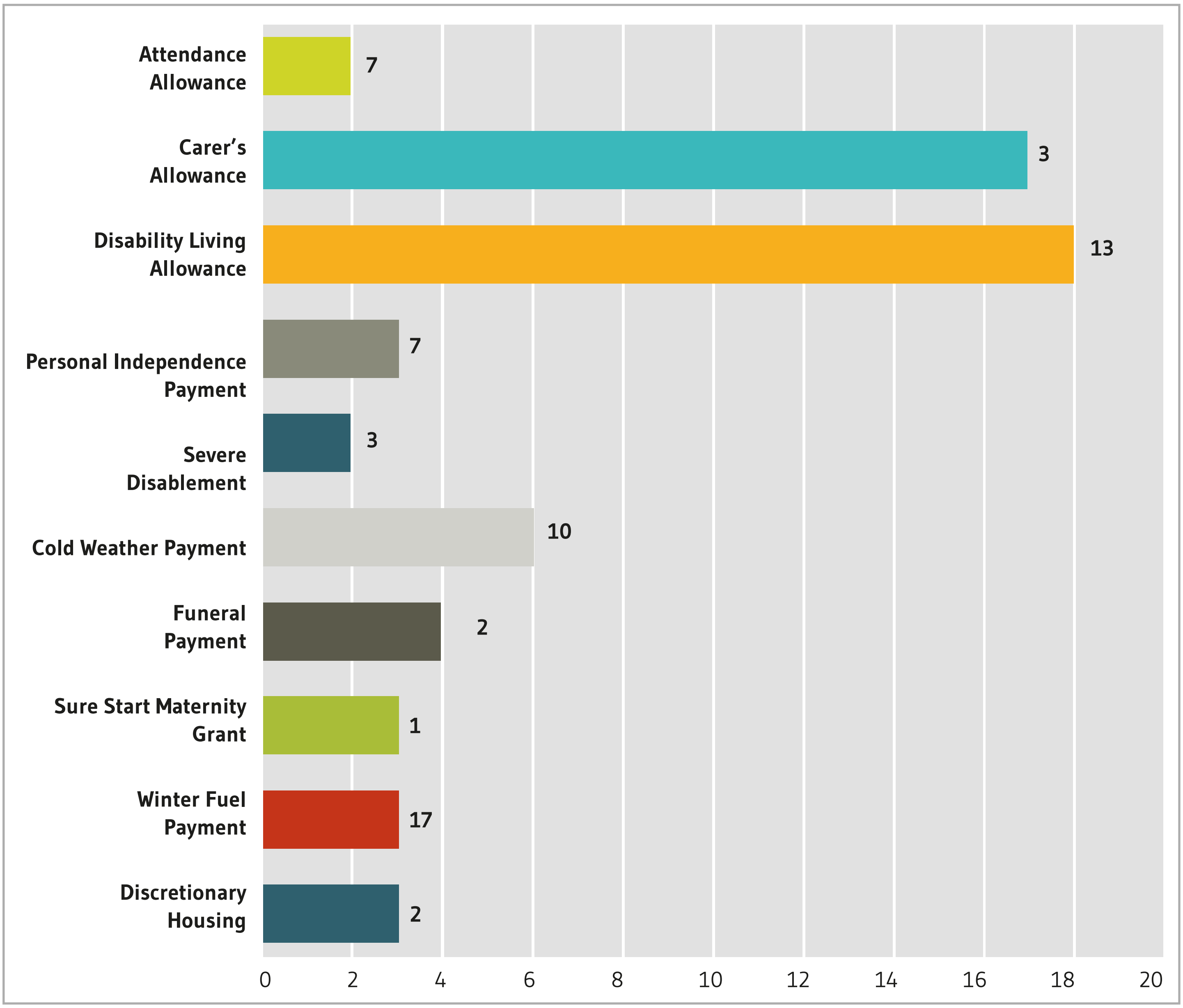
> *"You need to be seen as a person"*

> *"They don't necessarily need to be an expert in the particular long term condition but they need to have access to / contact with people who are"*

People aged 65+

Survey respondents

Experience of social security



Self-identification

Answer Choices	Responses	
Rural/remote dweller	29%	8
Sensory impairment/multiple conditions	54%	15
Mental health issues experience	21%	6
BME community member	7%	2
LGBT+ community member	4%	1
Unpaid carer	14%	4
Long term condition	4%	1
Physical disability	11%	3
Total Respondents: 28		

Gender identity

54 per cent female

46 per cent male

Views

Lifetime assessments

Most respondents recognised the need for an assessment of some form, though disagreed about how it should be carried out. Some felt a detailed assessment was necessary, whilst others said that a "conversation" or an online process could be better. A number of respondents said that long term, degenerative conditions shouldn't require more than one assessment.

Culture, behaviour, attitudes and skills

The person carrying out the assessment should have relevant experience of the long term condition experienced by the person attending the assessment. Not only should this involve an understanding of the person's circumstances and needs, but they require ongoing training and knowledge in development of these conditions.

Some people noted the importance of the words that are used during the process. It was noted that the term "assessment" could be replaced by a much more positive term such as "conversation".

Information and communications

People should be able to access information about the progress of their claim following an assessment. Some respondents said that this could also allow for a route to note changes in personal circumstances following an assessment.

Alongside a quick response, respondents also requested that clear information of the reasons for the decision should be included, alongside any particular consequences this might have for passported benefits (such as entitlement for Carer's Allowance).

Personal support, independent advocacy and advice

Some respondents were keen to point out that the assessment should be made as simple as possible to avoid the need for support, but others noted the need for a "central mediator" to work between the assessor and the person. This should also involve discussions with GPs and Social Work staff who know the individual. Others who could also be involved in supporting the person through an assessment include Scottish Government advisers, lawyers skilled in disability, health visitors and benefit advisers.

Many survey respondents said that they required additional support in order to complete the forms required of them during the existing process. Any new system should build in a requirement for advice workers, welfare rights workers and peer support to enable people to complete the forms as comprehensively as possible at the first attempt. Outreach staff and independent advocacy may also be required.

Assessment meetings

Assessment centres require to be accessible to people with a range of long term conditions, including vehicle space and interpreters for people with sensory impairments.

Deadlines and timelines

Some respondents suggested that "instant" decisions should be available on entitlement but others said that the Scottish Government should simply be required to establish a clear timescale which must be followed. This should also be the case for the appeals process.

Financial support

Some respondents noted concerns about changeover in entitlement between Disability Living Allowance and Personal Independence Payments. In some circumstances delays had left people without support for a month or more. Any new system should ensure that there is a smooth transition between entitlements that addresses the person's views and requirements.

> *“A mechanism needs to be in place to ensure impartiality and proper professional standards in the assessment process.”*

> *“Person conducting conversation should be sensitive and not patronising and also tell claimant exactly what their rights are and what they are entitled to.”*

> *“Independent organisations (should be involved) with flexibility for the assessors. Not everyone fits into a neat box.”*

> *“Only employ best people for the job in hand. Properly trained experts that know what they are doing and the consequences of their actions.”*

> *“The whole process must be based on honesty and if a client is found to have claimed fraudulently they should have to pay it back at a realistic rate.”*

Members of the Gypsy/Traveller community

Survey respondent

The one survey respondent who indicated they are a member of the Gypsy/Traveller community also indicated that they have experience of sensory impairment/multiple conditions and lived experience of mental health issues. They were a female aged 16-24 years, with experience of PIP.

In terms of assessing eligibility, this respondent indicated that their doctor has already reported they are too ill, and "who is more qualified than him?" They believe that a new Scottish social security system must be fair and person centred. Help with forms and assessments should be made available, and consulting doctors could help speed up the process. They need to be kept informed throughout the process using clear communications and information.

Focus group participants

With the support of Shelter Scotland, two members of the Gypsy/Traveller community who live in Midlothian took part in a focus group discussion. Both were women, one aged 45-49 and the other aged 25-34. They indicated experience of PIP, Discretionary Housing Benefit, ESA and Income Support. One of the participants also self-identified as having lived experience of mental health issues.

Views

Both participants believed that there should be an assessment process but it needs to be more accessible to people affected by mental health issues, who can find the process very stressful and intimidating. Participants also believed that entitlements should be awarded for longer time periods.

Information and communications

Focus group participants indicated that there needs to be a clearer explanation of the social security assessment process.

Personal support

Participants indicated that there should be more emotional support available to people during assessment meetings.

Culture, behaviour, attitudes and skills

Members of the Gypsy/Traveller community believe that the people who carry out assessments need specialist medical skills and training, particularly if the person being assessed has lived experience of mental health issues. There also needs to be more consideration given to the apparent gender imbalance. Assessors should also ensure they gather as much information as possible from the person's GP.

Assessment meetings

Assessment meetings need to run on time – sometimes applicants have to wait over an hour. This can be very stressful, particularly for those with mental health issues.

At the meeting, assessors should introduce themselves and give an outline of their qualifications. There needs to be a more relaxed environment created in the rooms where assessment meetings are held – they are often very sparse and uncomfortable. Assessment centres need to be made much more disabled and child-friendly. Support with child care could be made available, to facilitate participation in assessment meetings.

Deadlines and timelines

If an assessment meeting is required, the notice period needs to be shortened compared to the current system because this waiting time can be very stressful.

Survivor of trauma/abuse

The survey respondent who indicated they are a survivor of trauma/abuse also indicated they live in a rural or remote part of Scotland, have experience of sensory impairment/multiple conditions and lived experience of mental health issues. They identified as male, aged 35-44, with experience of Discretionary Housing Payments.

This respondent indicated that there should not be an assessment process and all their answers to subsequent questions reiterated this response.

Care experienced person

The survey respondent who indicated they are care experienced also indicated they have experience of homelessness. They identified as male, aged 16-24, with experience of Discretionary Housing Payments.

This respondent believed there should be an assessment process but it must be done by the right professional "as I know the assessment for medical applications is really bad." In terms of eligibility, decision-makers should be people with experience. Decisions should not be based on targets, but on helping people into work where appropriate. Advisors should be supportive during assessments, spend longer with clients and not treat them like robots. Continuing with the same advisor throughout the process would be best.

Recommendations

Based on the findings set out in this report and our other work on social security[6], the ALLIANCE proposes the following recommendations.

Piloting and testing

In light of Scottish Government statements, there is likely to be a significant change in approach in the delivery of social security from that adopted by the UK Government. As such, the ALLIANCE strongly recommends a period of piloting and testing that balances the need to provide uninterrupted entitlements alongside informed trials of different approaches and responsive adaptation.

Mainstreaming human rights

Seldom heard people have called for the new Scottish system to be fair and transparent, and for people to be treated with dignity and respect. We therefore welcome the Scottish Government's repeated commitment that social security will be underpinned by, and embed, such human rights principles[7].

Human rights provide a common language and unifying philosophy to apply the principles and practice of co-production, participation, person centeredness, equality, fairness, transparency, accountability, dignity and respect.

The ALLIANCE recommends that the new social security system uses the rights-based PANEL principles[8] to help 'sense check' at each stage of design, delivery, oversight and review. We also recommend that due regard be given to the obligation to fulfil human rights as well as respect and protect them. This means taking pro-active, positive steps to ensure enjoyment of all human rights, not simply refraining from infringing people's rights or preventing others from doing so[9].

The Scottish Government has already indicated its willingness to explore new ways of working with the introduction of the Social Security Experience Panels[10]. Mainstreaming human rights may also require innovative and experimental approaches. Guidance on how to operationalise the human right to social protection is available from respected international agencies like the United Nations and International Labour Organisation[11], and many organisations, including the ALLIANCE, are ready to support this work.

Culture change

A substantial proportion of people the ALLIANCE has consulted talked about the need to fundamentally change the culture of social security in Scotland – both at a national level, but also within the system itself.

Nationally, we need to change how people who access social security are portrayed and treated. As the country's principle human rights 'duty bearer'[12] the Scottish Government has a crucial role to play in leading this process so that people are seen as equal citizens entitled to the human right of social security, rather than 'scroungers' or charitable recipients of 'welfare' and 'benefits'.

The culture within the social security system itself must also shift to one that is person centred, supportive and compassionate – for those who access it and the people employed within it. The Scottish Government can play a vital role in modelling and enforcing a culture of respect and dignity that is mainstreamed throughout the new system and demonstrated by the language, behaviour and attitudes of everyone working within it. This should include investing in agency-wide training and development in interpersonal and communications skills, equalities and human rights, as well as ring-fencing support and supervision.

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6 See, for example, http://www.alliance-scotland.org.uk/news-and-events/news/2016/10/alliance-calls-for-supportive-social-security-in-scotland/#.WQXxVhPyt8w 7 https://www.holyrood.com/articles/news/social-security-be-human-right-new-bill 8 http://www.scottishhumanrights.com/in-practice/human-rights-based-approach/ 9 http://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx 10 http://www.gov.scot/Topics/People/fairerscotland/Social-Security/Experience-Panels 11 http://socialprotection-humanrights.org 12 http://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx

Ensuring independence and accountability

Many participants in the consultation project expressed deep concern about the role played, and often traumatic impact caused, by the involvement of target-driven and profit-making private sector in social security. The ALLIANCE therefore welcomes the Scottish Government's announcement that the new social security assessment process will not be run for profit or by the private sector[13]. We would encourage this commitment be embedded in law.

As expressed by many consultation participants, the ALLIANCE also recommends the creation of an independent oversight mechanism to monitor the new Scottish Social Security Agency.

Involving and empowering seldom heard people

The ALLIANCE strongly recommends systematic and ongoing inclusion of seldom heard people in the design, delivery, oversight and review of Scotland's new social security system. As we know, some sectors of Scottish society are disempowered and excluded from mainstream consultation processes. To ensure people's right to participate freely, actively and meaningfully in decision-making, the Scottish Government and other public bodies may need to take pro-active, creative and innovative steps to help empower and engage with excluded groups. Due regard must also be given to intersectionality: as this report clearly indicates, most consultation participants identified as belonging to two or more seldom heard groups.

Embedding co-production and continuous improvement

Above all, social security needs to work with and for the people who access it. The Scottish Government should use the opportunity of introducing a new system to move beyond consultation and engagement and put co-production firmly into practice.

We welcome the introduction of Experience Panels to gain direct insight from people accessing social security for the design and development of the new system, and note that these are due to start in summer 2017 and run for four years. To support continuous improvement of the new system, we recommend that a similar process be fully embedded beyond this. This should be co-designed with people to pro-actively seek their views, experiences and satisfaction levels on an ongoing basis. Feedback loops should be built in to ensure people are subsequently informed how their advice has been acted on and/or had an impact.

Information and communications

A public information campaign would help raise awareness about the changing social security system in Scotland and form part of the process to challenge stigma. A more tailored element of this would also help specific groups, including members of the BME, refugee and asylum seeking communities, unpaid carers and older people, to overcome the barriers they currently face in finding out about and accessing social security.

As we know, the right to information facilitates the enjoyment of all other rights. Therefore if people are not provided with clear information in a format tailored to their requirements, they cannot make informed decisions about the issues that affect them. It is crucial that all information and communications relating to the new Scottish social security assessment process is available in a range of different formats and tailored to people's different communication requirements.

We welcome indications from the Scottish Government that the new assessment system will give due regard to self-assessment and third party, professionally founded, supporting information[14]. Giving greater weight to information provided by applicants, and the people who know them best, will help re-establish trust in the new system. It will also help to streamline the process by facilitating applications via form only and reducing the number of unnecessary assessment meetings

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[13] https://news.gov.scot/speeches-and-briefings/social-security-agency [14] https://news.gov.scot/speeches-and-briefings/social-security-agency

and appeals. We would also recommend that greater regard be given to the insight of unpaid carers and peer supporters in the application process.

Independent advocacy

We welcome the Scottish Government's announcement that there will be local pre-claims advice and support[15] however there are some issues to consider to ensure that people get the right support when and where they require it.

Independent advocacy – as a distinct form of supported decision-making[16] – should be available to everyone navigating the new social security assessment process at any point in the journey. Urgent, additional, resources need to be directed towards this sector to ensure it is available and accessible to everyone. Consideration should be given to making independent advocacy a statutory requirement in the forthcoming Social Security Bill.

Independent advice

As with independent advocacy, sources of independent advice, for example Citizen Advice Scotland, also requires urgent, additional resources if they are going to be able to provide the right information to people when they require it.

Cross-sectoral and integrated approaches

As we know, there is a substantial connection between social security and other public services like social care, health, employability and housing. Many seldom heard people expressed the desire to see greater complementarity and coordination between these. We recommend that opportunities to develop and trial cross-sectoral and integrated approaches be built into the new social security system.

Guaranteeing lifetime entitlements

We welcome the appointment of a Scottish Government advisory body on disability and carers' entitlements[17], tasked with exploring options for lifetime entitlements amongst other things. The vast majority of seldom heard people we consulted advocated an approach where people with lifelong or life-limiting conditions, and the people who care for them, have access to lifetime entitlements with only one, initial, application process.

Applications and assessments

The vast majority of seldom heard people we consulted indicated that many applications could have been assessed using only an application form with supporting information, without the need for an additional interview. If a meeting is required, this should be primarily at the applicant's request, and it should fulfil several criteria, including (but not limited to):

- Providing or eliciting information that is additional to what is in the application form and in supporting information, not replicating or duplicating this.
- Flexibility and choice in the meeting date, time and location.
- The meeting should be more of a conversation than an interview; it should be supportive and designed to maximise entitlements rather than penalise.
- Applicants should be entitled to have support from people of their choosing at the meeting; be able to record meetings; and read/sign all notes/forms to indicate whether they agree with them or not (with no undue influence).

National oversight; local delivery

We welcome the announcement that the new Scottish social security agency will have a local presence so it is directly responsive to individual's needs[18]. This is a particular concern for people living in rural or remote Scotland, who experience problems with the current, overly centralised, system. They have called for a much more locally based, locally informed and accessible social security system.

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[15] https://news.gov.scot/speeches-and-briefings/social-security-agency
[16] http://www.siaa.org.uk/us/independent-advocacy/
[17] http://www.gov.scot/Topics/People/fairerscotland/Social-Security/Governance/Disability-and-Carers-Benefits-Expert-Advisory-Gro
[18] https://news.gov.scot/speeches-and-briefings/social-security-agency

Appendices

Appendix A – Online survey

Some parts of the social security ('welfare' / 'benefits') system are being changed. This means the Scottish Government will be responsible for some social security benefits.

The Health and Social Care Alliance Scotland (the ALLIANCE) has been asked by the Scottish Government to help them. We have identified that you may be able to help.

We want to know what you think about the assessment process for social security. This is the process that decides if someone is entitled to receive social security payments. We want to know what you think works now and what will work in the future when the system changes.

The Scottish Government have asked us to help them hear from people that don't normally get a chance to give their views. This includes:

- Living in rural and remote areas of Scotland
- Asylum seekers and refugees
- Having lived experience of homelessness
- Living with sensory impairment/ multiple conditions
- Having lived experience of mental health problems
- Being a member of the BME community
- LGBTQI
- Being a member of the Gypsy/Traveller community

This survey is anonymous. We need to ask some questions so we can make sure we get a mix of respondents.

*1. I have applied for, am paid or was paid the following social security payments. Please tick all the boxes that apply to you.

- Attendance Allowance
- Carer's Allowance
- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- Industrial Injuries Disablement Benefit
- Severe Disablement Allowance
- Cold Weather Payment
- Funeral Payment
- Sure Start Maternity Grant
- Winter Fuel Payment
- Discretionary Housing Payments
- Other (e.g. Job Seeker's Allowance) – please tell us which payment(s)

*2. I belong to the following group(s). Please tick all the boxes that apply to you.

- I live in a rural and/or remote area of Scotland
- I am seeking asylum and/or I am a refugee
- I have lived experience of homelessness
- I live with sensory impairment/multiple long term conditions
- I have lived experience of mental health problems
- I am a member of the Black and Minority Ethnic community
- I am a member of the LGBTQI community
- I am a member of the Gypsy/Traveller community
- Other – please tell us which group(s) you belong to

*3. I am aged

- Under 16
- 16-24
- 25-34
- 35-44
- 45-49
- 50-54
- 55-59
- 60-64
- 65 or older

*4. I am

- Male
- Female
- Trans
- Prefer not to say
- Other – please tell us how you prefer to identify

5. Should the new Scottish social security system include an assessment process? This would decide if people are entitled to receive social security payments.

- Yes
- No
- Please explain your answer

6. Who should decide if a person qualifies for payments in the new Scottish system as part of the assessment process?

7. What help or support should be available for the new assessment process?

8. What needs to happen before assessments for social security payments?

9. What needs to happen during assessments for social security payments?

10. What needs to happen after assessments for social security payments?

11. Do you have any other recommendations for the new social security assessment process?

Appendix B – Focus group facilitator guide

Consent

A separate Information Sheet and Consent Form should be given to every participant before the group starts. Consent forms for focus group participants are completed in advance by all those seeking to participate.

Introduction

1. **Welcome**

   Introduce yourself and the note-taker, ask participants to write their names on a sticky label while you make introductions and explain why we're here etc.

   Review the following:

   - Who we are and what we're trying to do
   - What will be done with this information
   - Why we asked you to participate

   Some parts of the social security ('welfare' / 'benefits') system are being changed. This means the Scottish Government will be responsible for some social security benefits. The Health and Social Care Alliance Scotland (the ALLIANCE) has been asked by the Scottish Government to help them. We have identified that you may be able to help because the Scottish Government have asked us to help them hear from people that don't normally get a chance to give their views.

   We want to know what you think about the assessment process for social security. This is the process that decides if someone is entitled to receive social security payments. We want to know what you think works now and what will work in the future when the system changes.

2. **Explanation of the process**

   Ask the group if anyone has participated in a focus group before. Explain that focus groups are being used more and more often in research.

   About focus groups

   - We learn from you (positive and negative)
   - Not trying to achieve consensus, we're gathering information

- No virtue in long lists: we're looking for priorities
- In this project, we are doing a survey and focus groups. The reason for using both of these tools is that we can get more in-depth information from a smaller group of people in focus groups. This allows us to understand the context behind the answers given in the written survey and helps us explore topics in more detail than we can do in a written survey.

Logistics

- Focus group will last about two hours
- Give an estimated finish time
- Feel free to move around or leave at any point
- Where is the bathroom? Exit?
- Help yourself to refreshments

3. **Ground Rules**

   Ask the group to suggest some ground rules. After they brainstorm some, make sure the following are on the list.

   - Everyone should participate if they can
   - Information provided in the focus group must be kept confidential
   - Stay with the group and please don't have side conversations
   - Turn off cell phones if possible
   - Have fun

4. **Turn on Recording Device (if being used)**
5. **Ask the group if there are any questions before we get started, and address those questions.**
6. **Introductions**

   - Go around table: please tell us your name and, if you want, a little bit about yourself

Discussion begins, make sure to give people time to think before answering the questions and don't move too quickly. Use the prompts to make sure that all issues are addressed, but move on when you feel you are starting to hear repetitive information. We want to hear what people think would work well in a future social security assessment process. Discussion might get stuck on what's not working well with current aspects of the whole social security system. Wherever possible, ask people to identify what needs to be changed about what's not working and specifically about what would work well in a future assessment process.

Questions

1. **Let's start the discussion by talking about whether the new Scottish social security system should include an assessment process? This would decide if people are entitled to receive social security payments.**

   Prompts:

   - *Is it good to have an assessment process?*
   - *Are there some 'conditions' or diagnosis that should or should not need one? E.g. dementia, life-limiting condition?*
   - *How often should there be assessments? E.g. should some diagnosis (that will never change) only require a one-time assessment?*
   - *Would it be better to have an alternative to social security, e.g. Citizen Basic Income*

2. **Who should decide if a person qualifies for payments in the new Scottish system as part of the assessment process?**

   Prompts:

   - *Who's the best person for you that should decide?*
   - *Should it be e.g. a medical person? Who?*
   - *Someone that works for the Social Security Agency?*
   - *You?*
   - *Who else?*

3. **What help or support should be available for the new assessment process?**

   Prompts:

   - *Independent advocacy*
   - *Independent advice*
   - *Accessibility issues*
   - *Language/translation*

- *What is the best communication methods – telephone, email, text, face-to-face meetings, websites?*
- *Medical help?*
- *Other?*
- *What about time?*
- *What about help completing forms?*
- *How people and organisations behave and attitudes.*

4. **What needs to happen before assessments for social security payments?**

Prompts:

- *What about the process of assessment – paperwork, meetings, how contact is made, notice of meetings, etc.*
- *Medical and other information – what's needed and what isn't.*

5. **What needs to happen during assessments for social security payments?**

Prompts:

- *Does there need to be a face-to-face meeting?*
- *If not, what else can be done?*
- *What would a good face-to-face meeting look like?*
- *How would a good meeting make you feel?*
- *Where would the meeting be?*
- *How long would it take?*
- *Who do you need to meet with?*
- *What should they be like?*
- *Do they need to know anything in particular?*

6. **What needs to happen after assessments for social security payments?**

Prompts:

- *What does a good process after you've been assessed look like?*
- *How would it make you feel?*
- *How long does it take? And what format does it take?*
- *Immediately after the assessment interview but also beyond, e.g. how long before you are told about your decision? Should you be told then?*
- *What if you disagree with the decision? What would a good appeal system look like?*

7. **Is there anything else we haven't discussed that you would like to say about a new social security assessment process?**

That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us.

If you have additional information that you did not get to say in the focus group, please feel free to let us know.

Materials and supplies for focus groups

- Information sheet and consent forms (one copy for each participants)
- Focus Group Discussion Guide for Facilitator
- Sticky labels for name badges and marker pen
- Pads & Pencils for each participant
- 1 recording device, batteries and extra tapes
- Notebook for note-taking
- Refreshments

Appendix C – Focus group note-taker guidance and template

- Firstly, many thanks for taking notes at this focus group!
- Please refer to the Facilitator's Discussion Guide, which gives info as to how the focus group should progress.
- All notes are anonymous – please don't make a note of anyone's name.
- It would be great if you could support the Facilitator to ensure that each participant is given an Information Sheet and a Consent Form, and gather completed Consent Forms at the end.
- Clarity and consistency in your notes are very important - we'll be using them days or weeks later when memories will have faded.
- We don't need verbatim notes: please capture the main points of what people say in relation to the 7 main questions – as set out on the following pages.
- Bullet points are fine, but if you think it's important to also capture some detailed points then please feel free to do so, particularly if you think someone is making a contribution that might differ from or what you've heard others say (either at this group or elsewhere).
- Please capture any quotes, well-said sentences or phrases that illustrate an important point of view because they are enlightening or eloquently expressed.
- Similarly, please make a note of non-verbals if they seem important (but don't make assumptions as to what they mean), e.g. head nodding, laughter, discomfort, pauses.
- Please flag if the same participant states an opinion multiple times to avoid over-emphasizing the view during analysis.
- Please note that some focus groups/participants may jump around the 7 questions rather than address each in a strict chronological order.

Q1: Should the new Scottish social security system include an assessment process? This would decide if people are entitled to receive social security payments.

Q2. Who should decide if a person qualifies for payments in the new Scottish system as part of the assessment process?

Q3. What help or support should be available for the new assessment process?

Q4. What needs to happen before assessments for social security payments?

Q5. What needs to happen during assessments for social security payments?

Q6. What needs to happen after assessments for social security payments?

Q7. Is there anything else we haven't discussed that you would like to say about a new social security assessment process?

Appendix D – Focus group participant information sheet and consent form

Thank you for agreeing to participate in this focus group. We are very interested to hear your views on what a new social security assessment process should look like.

The purpose of this meeting is to listen to your views on what a new social security assessment process should look like. The Scottish Government have asked us to speak with people who are not often asked for their opinions.

The information you give us is completely confidential. Your name will not appear in our report.

We would like to tape the focus groups so that we don't miss anything. The tapes will be destroyed after the group. Please let us know if you are happy for the group to be recorded.

You don't have to answer the questions and you can leave the group at any time.

Some of the information we talk about in the group will be private. We will ask participants to respect each other's confidentiality.

If you have any questions now or after you have completed the group please contact:

Lucy Mulvagh

Health and Social Care Alliance Scotland (the ALLIANCE)

349 Bath Street

Glasgow G2 4AA

Telephone: 0141 404 0231

Email: lucy.mulvagh@alliance-scotland.org.uk

Social Security Engagement Panels: Open Application to 12th May 2017

The Scottish Government are setting up 8 'Experience Panels' of people who have applied for or received any of the following benefits within the last 12 months. The Panels will help to design and test the new Scottish Social Security System to ensure it works for them.

- Disability Living Allowance / Personal Independence Payments
- Attendance Allowance
- Severe Disablement Allowance
- Industrial Injuries Disablement Benefit
- Carer's Allowance
- Funeral Expenses Payments
- Sure Start Maternity Grants
- Cold Weather Payments
- Winter Fuel Payments
- Discretionary Housing Payments
- Scottish Welfare Fund
- Universal Credit

Find out more:

- Email: SocialSecurityExperience@gov.scot
- Website: www.gov.scot/socialsecurity
- Video: https://www.youtube.com/watch?feature=youtube_gdata&v=BQRdGWcgyfA
- Facebook: https://www.facebook.com/TheScottishGovernment
- Twitter: @scotgovfairer #scotsocialsecurity

Application:

- Online form: https://response.questback.com/scottishgovernment/experiencepanels
- Print off form: http://www.gov.scot/Resource/0051/00514827.pdf (send to "Freepost Social Security Experience Panels" – no stamp required)

Support:

- Helpline (Freephone): 0800 029 4974 (includes translation)
- British Sign Language (BSL) users contact http://contactscotland-bsl.org
- Text: Prefix 18001
- SMS: 07467 447375

Please tick the boxes below and sign the form to show you agree to participate in this focus group. We need to ask these questions to make sure we have a mix of people taking part in our discussions.

I am aged

	Under 16
	16-24
	25-34
	35-44
	45-49
	50-54
	55-59
	60-64
	65 or older

I am

	Male
	Female
	Transgender
	Prefer not to say
	Other – please tell us how you prefer to identify

I have applied for, am paid or was paid the following social security payments. Please tick all the boxes that apply to you.

	Attendance Allowance
	Carer's Allowance
	Disability Living Allowance (DLA)
	Personal Independence Payment (PIP)
	Industrial Injuries Disablement Benefit
	Severe Disablement Allowance
	Cold Weather Payment
	Funeral Payment
	Sure Start Maternity Grant
	Winter Fuel Payment
	Discretionary Housing Payments
	Other (e.g. Job Seeker's Allowance) – please tell us which payment(s)

I belong to the following group(s). Please tick all the boxes that apply to you.

	I live in a rural and/or remote area of Scotland
	I am seeking asylum and/or I am a refugee
	I have lived experience of homelessness
	I have a disability
	I have lived experience of mental health problems
	I am a member of the Black and Minority Ethnic community
	I am a member of the LGBTQI community
	I am a member of the Gypsy/ Traveller community

	Other – please tell us which group(s) you belong to

	I understand the information I have been given and that I can ask questions if I need to.

	I understand that I don’t have to answer a question and I can leave at any time.

	I agree to take part in this focus group.

	I agree to the focus group being audio-recorded

	I agree that what I say can be used in a report, but not my name.

Name of Participant
Date
Signature

Name of Participant
Date
Signature

Appendix E – Focus Group details

Participants	No.	Partner	Location	Date
People with experience of homelessness	4	Glasgow Homelessness Network	Glasgow	24/02/17
Unpaid carers	4	Carers Trust Scotland	Glasgow	01/03/17
People affected by mental health issues living in rural or remote Scotland	11	HUG Action for Mental Health	Inverness	16/02/17
	7			20/02/17
	8			23/02/17
People affected by sight issues	7	RNIB Scotland	Edinburgh	08/03/17
People affected by hearing loss	4	Action on Hearing Loss	Glasgow	14/03/17
People with a learning difficulty	6	People First (Scotland)	Edinburgh	16/03/17
Members of the BME community	3	Coalition for Racial Equality and Rights (CRER), Poverty Alliance, RNIB Scotland	Glasgow	08/03/17
Members of the LGBT+ community living in rural or remote Scotland	9	Dumfries and Galloway LGBT Plus	Dumfries	22/02/17
	9		Stranraer	18/03/17
Members of the refugee/asylum seeking community	16	Saheliya	Glasgow	15/03/17
Members of the Gypsy/Traveller community	2	Shelter Scotland	Midlothian	13/02/17
Disabled people living in rural or remote Scotland	7	Scottish Disability Equality Forum Badenoch and Strathspey Access Panel	Boat of Garten	14/03/17

About the ALLIANCE

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 1,900 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care. Many NHS Boards and Health and Social Care Partnerships are associate members and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre; that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

A new social security assessment process for Scotland: the views of seldom heard people

RESEARCH REPORT | June 2017

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www.alliance-scotland.org.uk

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

The Scottish Government

disability confident
COMMITTED

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