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# Social Security Experience Panels - Attendance Allowance Discovery



**EQUALITY, POVERTY AND SOCIAL SECURITY**



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# Introduction

In October 2018, the Scottish Government carried out a survey and focus groups with Experience Panel members who told us they have claimed, or have helped someone else claim Attendance Allowance.

## Summary

### **Finding out about Attendance Allowance**

Participants found out about Attendance Allowance from various places. Some were persuaded to apply by family or friends, whilst others were advised to apply by doctors or support workers. Many participants did not know Attendance Allowance existed, or that it was an option for their particular condition.

Participants suggested that to increase awareness of Attendance Allowance, the benefit should be advertised in GP surgeries and other healthcare settings, as well as targeted engagement with third sector organisations such as charities or Citizen's Advice Bureau.

### **Applying for Attendance Allowance**

Focus group participants told us it took them time to come to terms with their support needs before they could apply. Filling in the form forced them to 'confront their new reality' and accept they could not go about their lives as they used to.

Many participants had applied on behalf of other people, such as their partner or parents. Participants acquired an application form from various sources, such as being posted to them by DWP, given to them by a carer or collecting it themselves from a JobCentre. Some participants told us that obtaining an application was a difficult experience.

The form itself was described as being 'confusing' and 'complex'. The repetitive nature of the form was seen as being 'daunting' and put some people off applying. Even participants who were used to completing difficult or complex forms as part of their jobs felt the AA form was difficult.

Despite the length of the form, many participants felt they did not get a chance to say what they wanted to say. Some felt the form missed out important questions, or that it did not give them space to talk about their health condition.

Many participants said they wanted to complete the application form online however keeping a paper form was also important.

Participants told us that they sent in varied supporting evidence when applying. This included evidence from their GP, consultant or other health professional, evidence from social and care workers and lists of medicines they were taking.

When asked if they would be happy with the agency gathering some supporting evidence for them (such as through data sharing), most participants were happy for this to take place so long as accessing the information was restricted to healthcare professionals.

## **Impact of Attendance Allowance**

Participants told us that Attendance Allowance helped them to maintain independence, supplement the additional day to day costs arising from their health condition and helped ensure their financial stability. In practice, this meant things such as purchasing meals and paying for taxis.

Participants told us the extra money 'made life a little easier' as things such as heating their home became more affordable. Several participants told us that without the benefit, they would not be able to meet their financial commitments.

When asked what they thought Attendance Allowance was for, most participants felt it was to help them to retain independence and to support them to continue to live in their own homes for as long as possible.

## **Background and research methods**

The Scottish Government is becoming responsible for some of the benefits previously delivered by the Department for Work and Pensions. As part of the work to prepare for this change, the Scottish Government set up the Social Security Experience Panels. Over 2,400 people from across Scotland who have recent experience of at least one of the benefits being devolved to Scotland registered as panel members.

The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland, based on the principles of dignity, fairness and respect.

To deliver the benefits devolved to Scotland, the Scottish Government have established Social Security Scotland ('the agency') who will be responsible for administering Scotland's new social security system. As part of the creation of the new agency, we have worked with Experience Panel members to understand their views on Attendance Allowance.

This report details the key themes which emerged from a survey and focus groups which took place in October and November 2018. The research considered:

- How participants found out about Attendance Allowance;
- Participants' experiences of applying for Attendance Allowance; and
- What participants use their Attendance Allowance payments for.

Participants were recruited from the Scottish Government Experience Panels. In recognition of the additional accessibility needs that are likely to be faced by this cohort, and to ensure that panel members were able to take part in the way that

was most suited to them, an initial opt-in survey was sent to panel members who told us they had experience of claiming, or helping someone else claim Attendance Allowance. This survey invited Experience Panel members to tell us their preferred way of participating in the research: completing an online survey or attending a face-to-face focus group.

Twenty-six panel members went on to complete the full survey and 10 attended a focus group. The majority of survey questions were free-text responses designed to match the information gathered in the focus groups. Due to the small response numbers, survey responses are discussed here only to give a very general idea of the views of this group of participants and should not be read as representative of the views of the wider population.

The Social Security Experience Panels are a longitudinal research project. The panels are made up of volunteers from the Scottish population who have experience of at least one of the benefits that will be devolved to Scotland.

## Finding out about Attendance Allowance

We wanted to understand where participants found out about Attendance Allowance.

Participants found out about Attendance Allowance from various places. Some were persuaded to apply for Attendance Allowance by family or friends:

'I was persuaded to apply to ease the pressure on family and friends who felt obliged to escort me when I was travelling outwith the immediate area of my home.'

Other participants were advised to apply by a doctor or support worker. This recommendation sometimes came following a hospital admission.

'My doctor advised me to apply initially. I had major surgery on my neck and was finding it very difficult to cope with everyday tasks. I needed supervision in case I fell or had problems dressing.'

Many participants did not know that Attendance Allowance existed, or that it was an option for their particular condition, until a professional signposted them to the benefit. This occasionally happened quite some time after the participant would have first been eligible to claim:

'I had to give up work to look after my dad full time and I did not know Attendance Allowance existed until five or six years later [...] It was only when I registered with my local carer's center that they pointed it out.'

Others only became aware of Attendance Allowance through their experiences of voluntary work:

'I only knew the benefit existed as a volunteer with a local CAB at the time.'

Some participants felt that many people did not apply for Attendance Allowance because of limited awareness:

I think there must be a lot of people who do not claim this benefit because they do not know about it. GPs and other local health staff should be promoting it. Councils should be sending out information when a person receives a package of care.'

When asked how to increase awareness of Attendance Allowance, participants suggested:

- Advertisements in GP surgeries, MSP offices and in hospitals;
- Targeted engagement with third sector organisations such as charities or Citizen's Advice Bureau; and
- Improved signposting through support networks.

## Names

A number of participants commented on the name of the benefit, feeling that it was inaccurate or didn't reflect what the benefit was for.

'The name suggests I need attending too. And often the person providing care feels they should be claiming for attending to the cared for person.'

## Applying for Attendance Allowance

Even if a person is aware of Attendance Allowance, it can sometimes take a long time before they feel they are able to submit an application. Some focus group participants told us they had to take time to come to terms with their support needs before they could submit the form. Filling in the form forced them to 'confront their new reality' and accept that they could not go about their lives as they used to do.

## Reasons for applying

Many participants had applied on behalf of other people, such as their partner or parents:

'I applied on behalf of my elderly mother whose general health was getting worse. As a former benefits advisor, I had more knowledge than average.'

'Application was for my husband who has been diagnosed with Parkinsons...'

'I applied on behalf of my mum and dad. Before they died, they both required a package of care and we wanted to top up the package to support them to remain in their own home for as long as possible.'

Overall, the findings suggest a relatively poor level of awareness of Attendance Allowance existed amongst participants and many did not apply until the health condition of the claimant resulted in them seeing a professional who recommended they apply.

## The application form

Participants acquired an Attendance Allowance application form from a number of sources, including:

- Being posted out to them from DWP;
- Given to them by a carer, friend or relative; and
- Collecting a form themselves from a JobCentre.

Some participants told us that obtaining an application form from a JobCentre was a difficult experience. The negative stereotypes and media portrayal of benefit claimants made them reluctant to be associated with the system.

Participants described the application form as 'complex' and 'confusing'. Some participants told us that the long and repetitive nature of the form was 'daunting' and put them off applying.

'The form (and questions asked) is too long and repetitive; this in itself is enough to stop some folks applying.'

'The form is confusing for elderly people and seems to ask the same questions in a different format. It can be very repetitive.'

The perceived repetitive nature of the form made some participants feel as if they had to justify themselves over and over again:

'Also in a degenerative illness, with no hope of improvement, [you] should not have to justify yourself over and over again.'

Many participants said that they had to seek support to complete the form from third party organisations or family members.

'I needed information from CAB, wouldn't have completed otherwise.'

'There's no way my parents could complete the form themselves. I completed a bit then read back to them what I had put.'

Even participants who were used to completing forms, or had experience in this area, told us that they found the form difficult:

'I am a retired bank manager and was used to filling in forms, but the application form for Attendance Allowance would have beaten me if I had not had help [...]. The length of the form is prohibitive and the questions asked seemed to be repetitive.'

A small number of participants who had previously worked for DWP and were familiar with such paperwork found the form more manageable.

Despite the length of the form, participants told us that they still didn't feel they had a chance to say what they wanted to say. Some participants felt that the form missed out important questions:

'The questions don't enquire about how you deal with daily tasks, only eating, washing and dressing. Nothing about how you get your medication, shopping, etc. Nothing about getting to a doctor or hospital appointments.'

'Some of the content seems to be missing, e.g. no account is taken of the ability or lack of, of being able to cook for oneself. It asks "can you feed yourself", not "can you prepare food".'

Other participants felt that the specificity of the questions limited their ability to describe the impact their health condition had on their lives:

The CAB helped me to complete the form as it was lengthy and didn't cover what I wanted to say.'

'The form concentrates on care needs but no clear part on disabilities due to mental health (such as dementia) and as mobility is not a consideration.'

This 'specific' nature of the questions was particularly problematic if the form was being completed on behalf of someone else. Some participants told us they felt as if the application was 'intrusive', especially where they were completing the form on behalf of a family member:

'The questions were very intrusive and hard to complete because I am my husband's appointee. As I answered the questions truthfully, I felt I was betraying his confidence, writing down the reality of his most personal upsets. I felt terrible. [...] It made me feel very disloyal...'

This was especially the case where the applicant had to describe or answer particularly personal questions, such as toileting needs and the support needed.

Answering the questions from the point of view of a family member was also perceived as challenging:



'I was completing the form on behalf of my husband so I had to answer the questions from his point of view, which was not always easy.'

Some participants felt it was difficult to describe their worst days in such detail:

'It's difficult for some people, like me, to be negative about the limitations of a chronic, incurable condition. However we are advised to state what life is like on our worst days.'

When asked how to improve the form, many participants said it should be shorter, easier to understand and less repetitive. Some suggested that an improved form should have more generalised questions to allow applicants to talk about their condition in their own terms.

'More generalised questions about support needed. Not concentrating on specific actions.'

Others wanted the form to be more easily accessible, for example online:

'Easier to access the form and shorten the length of it.'

It was felt that if the application form was offered online, it was still essential to ensure that paper or face to face application was still available so as not to exclude elderly applicants or those uncomfortable using a computer:

'Would be useful to be able to complete it [application form] online as well. Given the age group, essential that help is offered to complete the form face to face if this is requested.'

Others told us that better guidance on how to complete the form would be useful. Many participants were unclear as to whether they should answer as to how their condition was at the present time, or if they should describe their condition at its worst:

'Clarity in the instructions could be helpful.'

Participants told us that they hoped the benefit would be easier to understand when it transferred to Social Security Scotland.

'Hopefully the Scottish version of AA will be easier to understand and claim.'

## Supporting evidence

We asked participants whether they sent in supporting evidence with their application form. Over two thirds of survey respondents said they had sent in evidence. Respondents told us they sent in a range of evidence, including:

- Evidence from their GP, consultant or other health professional;
- Evidence from a social worker or care worker; and
- A list of medicines they were taking.

In the future, the agency may be able to gather some evidence to support Attendance Allowance applications for clients. This might include a list of medicines they are taking. To do this, data would have to be shared between healthcare providers and the agency.

Participants were mostly happy for this data sharing to take place, so long as the information was restricted to healthcare professionals:

‘I would be fine with it only being seen by health professionals.’

Some participants highlighted that many applicants would not have recent interactions with the health service as their health condition had reached a stage of being managed rather than treated:

‘For instance, people with Osteoarthritis do not attend the Rheumatology department and only see a doctor when pain or depression meds require a top up. Many people with OA and related MSK <sup>1</sup>conditions do not see any health professionals as they think they “just have to get on with it”.’

## Contact with DWP

We wanted to understand if participants had been contacted by the Department for Work and Pensions as part of their application. Almost two thirds of survey respondents had been contacted by DWP, as had many focus group participants.

Participants gave varying reasons for the contact, including:

- Confirming the award or to notify the applicant they were successful;
- Enquiring to resolve an issue on the application form; and
- Requesting further information about the condition.

Few participants commented on their interaction with DWP, however a small number spoke positively of their interaction:

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<sup>1</sup> Musculoskeletal

‘DWP were very helpful. My mother’s condition was changing rapidly during the several weeks from starting the application to submitting it, such that it became necessary for me to be a DWP appointee. DWP were very helpful in advising on how to arrange this.’

‘I am aware of the complexity of the governing legislation, and consequently appreciate the time and skill required to assess the application. Nevertheless, I was treated (relatively) fairly.’

Other participants had more negative views, describing the contact as ‘intimidating’. Some participants felt that letters from DWP were ‘implicitly threatening’ and they caused additional anxiety in what was already a difficult time in their lives.

The letters themselves were seen to be ‘complex’ and it was felt that a large portion of the letters’ text did not apply to the recipients. It was suggested that tailoring the letters to the claimant’s circumstances would increase understanding and make them easier to read.

### **Other potential improvements**

A small number of participants suggested other improvements to the benefit they would like to see. One participant suggested the benefit should be better linked to other potential services, such as blue badges:

‘Link up AA with other support, e.g. blue badges. In severe cases of mobility, a named carer can apply for a discounted mobility scheme car / scooter / wheelchair.’

## **Impact of Attendance Allowance**

In order to gain a greater understanding of participant’s expectations and views on Attendance Allowance, we asked them to describe in their own words what they thought the benefit was for and the impact the payments had on their lives.

Participant views varied little and were generally consistent across the survey and focus groups. Responses generally fell into three groups and can be summarised as: to maintain independence, to supplement the additional costs resulting from health conditions and to ensure financial stability.

In practice, this meant the money often went towards paying for taxis, supporting care costs and purchasing meals.

‘To meet the additional costs of everyday life. Poor health means I can’t cook, so were [sic] possible I buy in meals, I need to taxi everywhere, so that’s another cost.’

‘The financial payment assists pensioners to pay for help with their care, cleaners, use of taxis to get from A to B. The payment can also help them buy household furniture or equipment to ease or help their illness/disability.’

Participants told us that the additional money ‘made life a little easier’ as things such as heating became more affordable:

‘It makes life a little easier by ensuring that help is on hand when needed. It means that I can turn the heating on.’

We heard from several participants that without the benefit, they would not be able to meet their financial commitments:

‘Without it, I could not pay my bills and get a companion bus pass.’

‘We would not survive financially without it since I had to give up work.’

Many participants felt Attendance Allowance was to help them maintain independence, such as through supporting them to live in their own homes:

‘To allow a person who requires assistance to remain in their home and function as well as possible and as nearly as possible to those without life limiting conditions.’

‘To support people to remain in their own homes, as independently as possible, for as long as possible.’

## What’s Next?

The Scottish Government will continue to work with the Experience Panels in the development of Scotland’s new social security system. This will include further research on individual benefits in addition to cross-cutting work to assist in the development of Social Security Scotland.

The findings from this report will be used to inform the ongoing development and design of Attendance Allowance.

### How to access background or source data

The data collected for this social research publication:

- are available in more detail through Scottish Neighbourhood Statistics
- are available via an alternative route <specify or delete this text>
- may be made available on request, subject to consideration of legal and ethical factors.
- cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



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