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# Estimating the Impact of the New Definition of Terminal Illness for Disability Assistance in Scotland



**EQUALITY AND WELFARE**



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## Executive Summary

This paper provides estimates of the number of people who will receive Disability Assistance because they are terminally ill. It gives the estimated additional number of people applying for and being awarded each disability benefit and the total number of people receiving the assistance at any one time under the new guidance for Child Disability Payment (CDP), Adult Disability Payment (ADP) and Pension Age Disability Payment (PADP).

Social Security Scotland will have a different definition of terminal illness to that currently used for DWP disability benefits. Under the DWP system someone meets the definition if they have a progressive disease where death as a consequence of that disease can reasonably be expected within 6 months. The definition in Scotland will be that the progressive disease can reasonably be expected to cause the individual's death, with no expectation of the timeframe, but the disease should lead to an increased need for additional care and support.

We carried out a Delphi exercise with medical professionals who have experience of the current system under DS1500 rules. Delphi is a method for reaching consensus through a series of iterative surveys with experts on a subject. We shared the new guidance with the medical professionals, which details the change to the definition of terminal illness, and we asked how they thought this would affect the number of people eligible because they are terminally ill. They completed three surveys and between each one they were shown anonymised responses from the other panellists and asked if they wished to alter their response. This led to increasingly similar responses across the panel. The results of these surveys were used to estimate the impact of the new guidance on how many people of different ages with different conditions will apply because they are terminally ill.

There are a number of caveats to consider when interpreting these results. The assumptions provided through the Delphi exercise is the opinion of one group of medical professionals and there were variations in opinion between these experts. Another group of experts may have reached a different conclusion.

There is also uncertainty and judgements made when modelling the information from the Delphi panel. Central estimates have been produced using the average answers given by the panel but the actual figures could be higher or lower.

We estimate that the number of people who would be successful in their application for Disability Assistance because they are terminally ill might increase by around

90%. The number of people receiving Disability Assistance at any one time because they are terminally ill could triple.

The increase is driven by ADP and PADP and is a mixture of people who would have applied under DS1500 rules receiving the assistance earlier and people applying and receiving one of the benefits who wouldn't have under the DS1500 system. This could be because they weren't eligible, or could be a result of an increased awareness because of the change in definition.

## **Background**

If an individual has a terminal illness their application for Disability Assistance can be processed under "special rules". This will allow them to access the disability benefit faster, receive the highest rate of award, and removes the need to have had the health condition for any length of time. To qualify due to terminal illness an individual will require a medical practitioner to complete the Benefits Assessment Under Special Rules in Scotland (BASRiS) form. Currently, under the UK rules for disability benefits, medical practitioners use the DS 1500 form.

The DS 1500 form applies to the three current disability benefits; Child Disability Living Allowance (child DLA), Personal Independence Payment (PIP) and Attendance Allowance (AA). These benefits will be replaced by Child Disability Payment (CDP), Adult Disability Payment (ADP) and Pension Age Disability Payment (PADP) respectively, under which the BASRiS form will apply.

In the current UK DWP Social Security legislation, a person is deemed terminally ill if they suffer from 'a progressive disease and their death as a consequence of that disease can be reasonably expected within six months'. In Scotland, under the Social Security (Scotland) 2018 Act, a person will be deemed to have a terminal illness if it is the clinical judgement of an appropriate healthcare professional that they have a progressive disease which can reasonably be expected to cause their death.

To meet this definition of terminal illness for benefit eligibility the individual should have an illness:

- that is advanced and progressive or with risk of sudden death, and;
- that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, and;
- that is leading to an increased need for additional care and support.

As this definition does not include the 6 month time limit it is possible that more people will be eligible under BASRiS rules than DS1500, and that the people who are eligible under BASRiS could receive disability benefits due to terminal illness for longer than if they'd received it under the DS1500 rules. This paper sets out the potential scale of these changes to the number of people successfully applying for Disability Assistance due to terminal illness and the number of people receiving Disability Assistance due to terminal illness at any one time.

## **Delphi Methodology**

Earlier analytical work established that there is limited existing data we could use to quantify the impact of the new guidance on the number of people who would qualify for Disability Assistance under terminal illness rules. This is due to a number of reasons, one of the most significant being uncertainty around how medical professionals will apply their judgement.

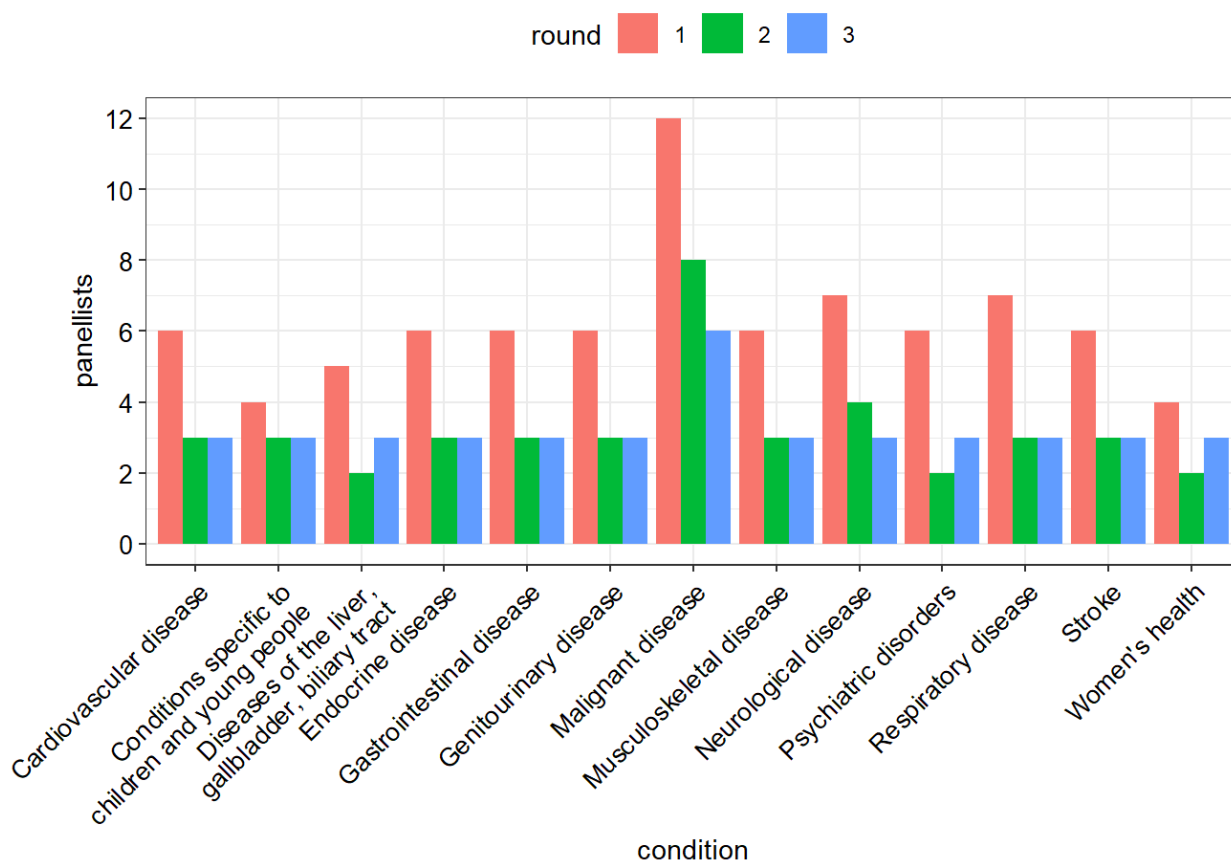
The Delphi method was identified as a suitable approach to collect and analyse the opinion of medical professionals on the impact of the new guidance on the number of people eligible for Disability Assistance because they are terminally ill.

The Delphi technique is a way of obtaining a collective view from individuals where there is little or no definitive evidence and where opinion is important. This took the form of a series of three iterative questionnaires answered by an anonymous expert panel consisting of doctors and nurses with experience of completing the DS1500 form.

After each survey, or "round", the panel's responses were anonymised and summarised and with this information the panel were invited to re-evaluate their response in light of the replies given by the other experts. Over the course of the surveys the panellists responses got more alike.

The panel consisted initially of 15 experts with experience of a variety of conditions. Over 99% of the people currently receiving PIP because they are terminally ill have one of these conditions as their main disabling condition. Some panellists dropped out over the course of the surveys, and the third survey had seven respondents.

The chart below shows the number of panellists with experience of each condition from each round of the research.



## Delphi Findings

The panel agreed that, depending on the condition, the number of people eligible because they are terminally ill would either stay the same or increase. The main reasons given why there could be an increase in the number of people eligible were:

- Removing the expectation that the patient is likely to die in the next 6 months.
- For conditions other than malignant disease, clinicians and patients may not be aware that they are currently eligible for benefits if they are terminally ill, and the new guidance might raise awareness of the ability to apply under this route.
- Clinicians may be more prepared to discuss with their patients that their condition is incurable and present the option to apply under terminal illness rules when not constrained by needing to provide a prognosis of 6 months or less.

We asked the panel to estimate how the number of people eligible due to terminal illness might change. A 100% increase would mean the number of cases double. The average responses in the third round of the survey is shown in Table 1.

Table 1 – Estimated increase in eligibility due to terminal illness by condition

Condition	Increase in eligibility
Frailty (along with one or more co-morbid conditions)	132%
Respiratory disease	100%
Malignant disease	92%
Stroke	82%
Renal disease	64%
Neurological disease	62%
Cardiovascular disease	53%
Diseases of the liver, gallbladder, biliary tract	28%
Psychiatric disorders	27%
Endocrine disease	16%

There were some conditions where most of the panel (over 70%) responded that there would likely not be a change in the number of people eligible. These were gastrointestinal disease, genitourinary disease and musculoskeletal disease. As this was not unanimous, a small increase of 5% was assumed for these conditions.

It should be noted that the conditions included in PIP data are described as the “main disabling condition” and there isn’t any information on the other conditions a person could be experiencing. The panel suggested that, for example, where someone is terminally ill and has diabetes, it’s likely they are terminally ill because of a complication, such as heart failure or renal disease. They commented that it is likely these complications would lead to the increase in eligibility for those with endocrine disease rather than being eligible through diabetes itself.

The panel agreed that people who would have received benefits because they are terminally ill under DS1500 will likely apply for benefits earlier under the BASRiS

guidance. This is due to the removal of the 6 month time limit, and would mean they receive the benefit for longer. The panel estimated that people would be eligible 10 months earlier than they are currently.

Analysis of the number of people currently receiving and successfully applying for PIP due to terminal illness suggest that, despite the 6 month rule, on average people receive PIP because they are terminally ill for around 16 months. The responses from Delphi suggest anyone successfully applying for ADP under the BASRiS rules would on average receive ADP due to terminal illness for 26 months.

## **Estimating the impact on successful applications**

Given the limited data available, applying the responses from the Delphi study is our best indication of how the BASRiS guidance might impact the number of people receiving Disability Assistance because they are terminally ill. However, there is considerable uncertainty when applying the Delphi output.

As with any Delphi exercise, the results are the synthesis of opinion of a particular group of experts, and surveying another group may have resulted in different figures.

Data is available on the main disabling condition of people receiving PIP because they are terminally ill. This shows over 80% of individuals receiving PIP because they are terminally ill and over 90% of people successfully applying for PIP due to a terminal illness have malignant disease. Estimating the impact of the new guidance on individual conditions other than malignant disease is very uncertain given the small volumes involved. Therefore, for ADP, this analysis considers malignant disease separately as the main driver of any changes, and looks at all other conditions as a group.

Given the responses from the panel shown in Table 1, this leads to an assumption that for ADP the number of people successfully applying due to terminal illness will be 92% higher than PIP for those with malignant disease, and 57% higher for all other conditions. When combined, this would equate to a 90% increase in the number of people successfully applying for ADP because they are terminally ill.

Currently in Scotland around 25 people receive child DLA due to terminal illness and no information is available on their conditions. The panel estimated that the number of successful applications for CDP would be 10% higher than for child DLA.



Similarly, no information is available on the conditions of people receiving AA because they are terminally ill, therefore the overall assumption for the ADP increase of 90% is used for PADP.

The corresponding number of successful applications by people who are terminally ill this would lead to, and the current number under the DS1500 rules, are shown in Table 2.

Table 2 – Successful Applications

Application type	Adult Disability Payment - Malignant Disease	Adult Disability Payment - Other conditions	Adult Disability Payment - Total	Pension Age Disability Payment	Child Disability Payment	All benefits
DS1500 successful applications per month <sup>1</sup>	180	20	200	190	3	390
Estimated BASRiS successful applications per month	350	30	380	360	3	740

Totals may not sum due to rounding.

These estimates would mean the number of people receiving Disability Assistance because they are terminally ill would triple. This would be a culmination of the increased applications, but also that people would receive the assistance for an additional 10 months (around 60% longer than in the current situation).

The panellists agreed that any increase in the number of people eligible due to terminal illness would be more likely to affect older people, but this is difficult to model given the lack of information on the conditions of the people receiving AA because they are terminally ill. One possible source of information from the panellists on the effect on older people is the estimates given for frailty as a condition. The panel estimates successful applications due to terminal illness from individuals with frailty (along with one or more co-morbid conditions) would increase by around 130%, the highest estimate of any condition. This may suggest the estimates for PADP could be increased instead of using the same estimates as for ADP.

<sup>1</sup> [Stat Xplore](#), accessed May-21

## Estimating the impact on the number of people receiving Disability Assistance

For ADP, we can estimate the increase in the number of clients due to BASRiS by splitting clients into three groups:

- People who would have received the assistance under DS1500, but due to BASRiS will receive it for longer. This is because they can apply earlier, before they have a prognosis of 6 months.
- People who are terminally ill but would not have applied under DS1500 and would have received the assistance under general rules. These are people who, under the DS1500 system, applied under the general rules rather than special rules for terminal illness, but will apply under special rules when BASRiS is introduced.
- New clients who would not have received disability benefits, under either the general rules or special rules for terminal illness, without the introduction of BASRiS.

To calculate how many people would have received assistance under the general rules but instead apply under BASRiS, we considered how many people currently move from receiving assistance under general rules to special rules for terminal illness and assume this will increase by around 90%, the same as the overall assumption for the increase in people successfully applying due to terminal illness. This means we are assuming the same increase in successful applications from both people who are new to the assistance or people who are already receiving the assistance under the general rules changing to receive the assistance under special rules for terminal illness. Information on the number of people who change from receiving assistance under the general rules to receiving because they are terminally ill isn't available for AA or child DLA.

The outputs from the Delphi study suggest around half (55%) of the estimated ADP clients receiving the assistance because they are terminally ill would have also received it under DS1500 rules, but due to BASRiS receive it for longer. Around 15% of the people receiving ADP because they're terminally ill wouldn't have received it through DS1500 rules but would have received the assistance under the general rules. The estimated remaining 30% of people wouldn't have received ADP without the introduction of BASRiS.

For PADP and CDP, given the lack of information available on how people move from receiving assistance under the general rules to receiving assistance because they're terminally ill, we assume that anyone who wouldn't have received assistance under DS1500 is new to the benefit.

The estimated number of people who will be receiving disability assistance at any one time because they are terminally ill is shown in Table 3.

Table 3 – Number of clients receiving assistance because they are terminally ill once all types of Disability Assistance are being delivered

Client Breakdown	Adult Disability Payment - Malignant Disease	Adult Disability Payment - Other conditions	Adult Disability Payment - Total	Pensioner Adult Disability Payment	Child Disability Payment	All benefits
BASRiS clients who would have received assistance through DS1500	4,300	800	5,100	4,900	53	10,100
BASRiS clients who would not have received assistance under DS1500, but would have received assistance through general rules	1,400	60	1,500	-	-	1,500
BASRiS clients who would not have received assistance under DS1500 or the general rules	2,500	400	2,900	4,400	5	7,300
Total estimated BASRiS clients	8,200	1,300	9,500	9,300	59	18,800

Totals may not sum due to rounding.

## Comparing to other data on terminal illness

To validate these results we can compare the estimated number of successful applications from applying the Delphi output to the limited available data on the number of people with health conditions and deaths. This can help us decide how likely these estimates are a reasonable expectation of what might happen. This is mostly focussed on malignant disease since it is such a large driver of the results.

The estimated number of people successfully applying suggest that there would be around 4,200 deaths per year of people who were receiving ADP because they were terminally ill with malignant disease.

Statistics are available on the number of deaths in Scotland where the cause of death is malignant neoplasms. The number of people with this cause of death in

2019, between the ages of 15 and 64, was around 3,400 and there were a further 4,400 deaths from people aged 65-74<sup>2</sup>.

PIP special rules clients are mostly people aged 16-64, but around 18% are 65 and over<sup>3</sup>.

This suggests the estimated number of successful applications to ADP each month by people who are terminally ill with malignant disease is plausible, if the number of people who stop receiving the assistance on their death includes a number of people over 65. The number of deaths in 2019 due to malignant disease for people under 65 infers that at least 800 of the deaths each year from people receiving ADP because they are terminally ill are people aged 65 and over. There would be an estimated 1,500 people aged 65+ receiving ADP due to terminal illness, so this number of deaths each year is possible, but implies that this age group receive ADP because they are terminally ill for a smaller amount of time on average than younger individuals.

For PADP we are estimating that around 4,300 clients receiving the assistance because they are terminally ill with any condition will die each year. For people aged 65 and over there were over 45,000 deaths in 2019<sup>2</sup>. Not all of these will have been due to a terminal illness, but our estimate is well within the total number of deaths in people age 65 and over. There were around 13,000 deaths in this age group from malignant disease alone in 2019.

Similarly, there were 67 deaths in children aged 1-14 in 2019<sup>2</sup> which did not have an external cause, such as accidents, which is above our estimate for the number of people receiving CDP because they are terminally ill who would die each year (around 40 children).

We can also compare the estimated number of successful applications made by people with malignant disease and the number of people with a cancer diagnosis each year. Currently there are around 4,100 people with malignant disease who start receiving PIP in Scotland each year. Just over half of these are people successfully apply due to terminal illness. Some of these people applying under special rules for terminal illness might not actually be new to receiving ADP because they are already receiving it through the general rules.

The Delphi results suggest there would be an additional 2,000 successful applications made by people terminally ill with malignant disease each year under BASRiS. However some of them may be people who, without the introduction of BASRiS, would have applied under the general rules, so reaching an overall figure

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<sup>2</sup> National Records of Scotland, [Vital Events Reference Tables 2019](#), Table 6.02

<sup>3</sup> [Stat Xplore](#), PIP Cases with Entitlement, accessed May 2021

for the new recipients of ADP with malignant disease each year is difficult. A possible high estimate would be around 6,100 people, but this may double count some people who successfully applied under the general rules in the same year.

In 2019 in Scotland around 12,000 people aged 15-64 and 5,000 people aged 65-69 were diagnosed with cancer<sup>4</sup>. The estimate of around 6,100 new clients seems plausible in this context of the number of people with a diagnosis each year.

We can't make the same comparison for PADP or CDP since there is no information available on the conditions of the people receiving assistance because they're terminally ill for AA or child DLA.

We can consider the total number of people receiving Disability Assistance who have malignant disease and how this relates to cancer prevalence in the population.

The Delphi estimates suggest the number of people who will receive ADP because they're terminally ill with malignant disease will increase to around 8,200 clients. Around 2,000 of these people would be individuals who would have otherwise received assistance under the general rules, but are either applying through the BASRiS rules earlier than they would have under DS1500 rules, or are applying under BASRiS where they wouldn't have under DS1500 rules.

Table 4 - Malignant disease clients

Application type	PIP malignant disease clients (Jan-21)	Estimated ADP malignant disease clients (steady state)
General rules	7,200	5,000
Special rules for terminal illness	2,400	8,200
Total	9,600	13,300

Totals may not sum due to rounding.

Estimates up to 31 December 2019 give the number of people in the population who are living with cancer as 76,000 for people aged up to 65, and 127,000 aged 65 and over<sup>4</sup>. Not all of these people would be considered terminally ill under the CMO guidance, but the Delphi estimates for terminally ill clients are well within these values.

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<sup>4</sup> Public Health Scotland, [Cancer incidence in Scotland](#), 11 May 2021

### **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
- may be made available on request, subject to consideration of legal and ethical factors. Please contact [social.research@gov.scot](mailto:social.research@gov.scot) for further information.
- cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



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