Implementation of CMO Guidance for fast-tracked access to disability assistance for those with terminal illness: analysis of effectiveness of implementation

1.   Situation

This scoping document aims to outline the analysis of the effectiveness of implementation of the CMO guidance supporting fast-tracked access to disability assistance for patients with terminal illness.

This document will be used to agree analysis between key stakeholders.

2.   Background

Provision of disability assistance has been devolved to Scotland and when the new forms of assistance launch, Scotland will administer new applications for disability assistance in a phased approach. Those already in receipt of disability assistance will transfer from The Department for Work & Pensions to Social Security Scotland in a similarly phased approach.

A proportion of those who apply for disability assistance are those who have terminal illness. For this group of clients 'Special Rules' may apply which fast-track applications and automatically provide the highest levels of assistance. As Scotland takes over administering this aspect of disability assistance and following extensive consultation, Scottish Government has widened the definition of 'terminal illness'. This was set in law in the Social Security (Scotland) Act 2018. See Table 1.

In order to support clinical judgements around terminal illness and supporting applications for fast-tracked disability assistance through completion of a BASRiS form, the Chief Medical Officer has produced guidance for clinical professionals. This guidance was developed by clinicians in a Short Life Working Group and a Stakeholder Reference Group and has undergone a managed consultation.

Table 1 Definitions of terminal illness for the purposes of claiming disability benefits

	Department of Work and Pensions (UK Government)	**Social Security Scotland**
Definition of terminal illness	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'.	A person is deemed terminally ill if it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death.

		An appropriate healthcare professional for this purpose is defined in legislation as a registered medical practitioner or a registered nurse.
Form used by a clinician to confirm an individual meets terminal illness definition	DS1500	BASRiS form

In order to demonstrate the effect of the change in definition of terminal illness and the effectiveness of the CMO guidance, an analysis of applications for disability assistance under Special Rules is planned. This document describes the initial scoping steps of that analysis. Scottish Government will undertake routine audit of applications and awards of disability assistance which should be viewed in conjunction with any analytical output described below.

This scoping document has been developed while the policies associated with disability assistance are at an early stage in development. While the broad assumptions underpinning it can be expected to remain largely the same, the scope and methods of analyses outlined may change in time as these policies are implemented and as the analytical requirements and associated feasibility become clearer post-implementation.

3. Key questions to answer

Is fast-tracked access to disability assistance for those with terminal illness fair, equitable and consistent?

- Is access equitable for all disease areas?
- Is access equitable for all ages (in proportion to Scottish demographic)?
- Is access equitable by sex?
- Is access equitable by ethnicity?
- Is access equitable by deprivation score?
- Is access equitable geographically?
- How do trends in access change over time for each of these?

How does fast-tracked access compare to standard route access to disability assistance for those with terminal illness?

- Are there differences in the disease areas of clients?
- Are there differences in the ages of clients?
- Are there differences between the sex of clients?
- Are there differences between the ethnicities of clients?
- Are there differences in the deprivation score of clients?
- Are there differences in the geographical distribution of clients?

Is the process of obtaining fast-tracked access to disability assistance for those with terminal illness of good quality?

- Is the guidance sufficient to support completion of BASRiS?
    - Have any complaints/suggestions/omissions been identified by users?
    - Are BASRiS forms being completed appropriately? Do any forms need to be queried for further completion or clarification?
    - Are any clients being refused fast-tracked access to terminal illness benefits? If so, why?
    - Has additional support been sought by direct access to Social Security Scotland or CMO Directorate (telephone or emailed queries)?
    - Feedback from users of the guidance obtained by survey could identify particular sections of guidance which is being interpreted in different ways in different situations.
- Who is using the guidance?
    - Is the guidance being used in primary and/or secondary care and/or the third sector?
    - What types of clinician are completing the form?
    - Is there unexplainable variation in use by clinicians geographically?
    - Are all disease areas represented by these clinicians?
- Is the award turnaround time from application to payment being met?
- Is the definition of 'terminal illness' being applied appropriately?
    - How long do clients receive the benefit after the award is made?
    - Is the processing time the same for all disease areas, age groups, sex, ethnic groups, deprivation scores, and geographically?
- Do clients have any feedback about the process of application, completion of paperwork, timeliness of decision-making and receipt of payments? As identified in any user surveys that Social Security Scotland may undertake or direct feedback they receive.

Questions to include in any qualitative work undertaken with those completing BASRiS forms

- Are you familiar with the CMO guidance supporting the completion of BASRiS forms?
- If yes, which sections were helpful?
- What additional information should be included in this guidance?
- If no, did you seek advice for completion of BASRiS? If so, from where?

4.   Data sources

BASRiS form – Data items in relation to applicant details, primary healthcare provider, details of parents, details of payment mechanism and diagnosis will be collected in section 1; clinical information where data fields are all free-text/essay-type responses will be collected in section 2; work to develop an electronic version of this form for completion on the web is underway as at March 2021.

User feedback –Analysts from Social Security Scotland plan to gather feedback from applicants/receivers of disability assistance following their application; this survey will principally be to understand respondents' experience with Social Security Scotland but there may be scope to put in specific questions to inform assessment of use of the fast-tracked access pathway.

Routine official statistics – Social Security Scotland will publish regular official statistics publications including information on applications received, awarded and paid for disability assistance.

Policy Evaluation - Analysts at the Scottish Government intend to share their approach to evaluating disability benefits shortly. Part of this approach will include analysis of those cases where the application for disability assistance has been made through the Special Rules route and where BASRiS information would be required. This activity may involve qualitative analysis to gather feedback from clients, those completing application forms and healthcare professionals completing/contributing to the BASRiS form.

5.   In-scope

Analysis of the implementation and utilisation of the CMO guidance for rapid access to disability assistance for those with terminal illness in Scotland.

6.   Out-of-scope

Analysis of the implementation and utilisation of disability assistance through the standard application route in Scotland.

7.   Stakeholders

CMO Directorate

Social Security Policy Team

Social Security Common Processes and Delivery Team

Scottish Government Communities Analysis Division

Social Security Scotland

National Implementation Group for Terminal Illness

Scottish Ministers

8.   Timelines

Due to the COVID-19 pandemic and redeployment of staff into emergency response, the initial goal of launch of phase one of disability assistance (Child Disability Payment) in summer 2020 has not been possible. At March 2021, launch of Child Disability Payment is planned for summer 2021 as part of a pilot, with full rollout by autumn 2021. Adult Disability Payment is planned for spring 2022 again beginning with a pilot, with full rollout in summer 2022.

The BASRiS paper form was finalised by the end of 2020. However, work on a digital form and potential links into existing medical information systems is still in progress as at March 2021. Work is progressing to clarify what information will be collected from the BASRiS forms and available digitally for analysis.

At March 2021, the SG Communities Analysis Division have undertaken a Delphi exercise which will be used to estimate the numbers of clients for whom a BASRiS form would be completed. This work was delayed due to the COVID-19 pandemic but is due to report in the first half of 2021 and will be used to inform planning before the launch of disability assistance.

Analysts at the Scottish Government intend to share their approach to evaluating disability benefits shortly and work is underway to define the scope and methods for relevant analysis.

At March 2021, it is anticipated that Social Security Scotland will publish routine official statistics about disability assistance, however, this is not yet described.

9.   Next steps

This document will be shared with the Scottish Government Communities Analysis Division and the Scottish Government Social Security Delivery Team. Overlaps with analyses in these teams have been identified and these team leads will feed this audit into any designs for routine Social Security Scotland audits of processes.

Next steps should be:

- To maintain contact with the Analysis and Social Security Delivery Teams.
- Ensure that relevant aspects of this audit continue to be included in the outputs of any analyses and audits these teams design.
- Work with these teams to implement this audit following the launch of Scotland's new forms of disability assistance.

Main author

Dr Alison Potts

Specialty Registrar in Public Health, Directorate for the Chief Medical Officer, Scottish Government

Contact Details

Social Security Policy - Meg Sydney – Meg.Sydney@gov.scot

Clinical: Dr P Mishra – Padmmini.Mishra@gov.scot

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