

Evaluation of Special Rules for Terminal Illness (SRTI) in the delivery of devolved disability benefits

Clinician and Practitioner Information Sheet

The Research Project

As part of a wider programme of work evaluating the policy impact of the devolution of disability benefits, the Scottish Government has commissioned KSO Research, an independent research company, to gather feedback on how changes to Special Rules for Terminal Illness (SRTI) in the context of the devolved disability benefits have been experienced by clients and clinicians, and to assess whether the introduction of SRTI is meeting its policy commitments.

We are writing to you in your capacity as a Registered Medical Practitioner (RMP) or Registered Nurse (RN) as someone who may be involved in the diagnosis and/or medical care of individuals with a terminal illness for the purpose of accessing disability assistance to invite you to take part in this research.

We want to hear from both clinicians who have direct experience of completing BASRiS forms or the DWP equivalent (SR1 or DS1500 forms) as well as those who are eligible to do so i.e., they have been involved in the diagnosis and/or medical care of individuals with a terminal illness.

Background

Where a child or adult living in Scotland has been diagnosed with a terminal illness under the Scottish definition, they may be eligible to apply for disability benefits under SRTI.

The Scottish definition of terminal illness is different to that used by the UK Government. The Scottish definition of terminal illness, for the purposes of accessing disability assistance, is "a progressive disease that can reasonably be expected to cause the individual's death". This definition removes the timescale currently used by the Department for Work and Pensions (i.e. that the patient is likely to die within 12 months). Instead, the judgement as to whether a person should be considered terminally ill for the purposes of determining eligibility for disability assistance is



made by clinicians (a doctor or nurse involved in an individual's diagnosis or care), based on guidance prepared by the Chief Medical Officer (CMO)¹.

Special rules apply to Child Disability Payment (CDP), Adult Disability Payment (ADP) and Pension Age Disability Payment (PADP).

What the research is about

One of the specific aims of the research is to understand how the Scottish terminal illness definition and associated guidance are understood and experienced by clinicians.

The things you would be asked about include:

- your understanding/awareness of SRTI, including the guidance, process, eligibility criteria and different medical evidence forms associated with SRTI;
- current barriers/facilitators to implementing SRTI where appropriate; and
- what further help or support would be useful to you and your colleagues in implementing SRTI.

How you can take part

As above, the Scottish Government is keen to hear from both clinicians who have direct experience of completing BASRiS forms or the DWP equivalent (SR1 or DS1500 forms) as well as those who are eligible to do so i.e., they have been involved in the diagnosis and/or medical care of individuals with a terminal illness. If this applies to you, we invite you to:

- complete a **short online survey** which asks about your experiences of SRTI the survey would take no more than 15 minutes to complete; **and/or**
- take part in a short telephone interview to discuss your experiences in more detail and explore what changes, if any, are required to the current process to make it more accessible for clinicians - the interview would last no longer than 15 minutes and would be by telephone or online, at a time that is most convenient for you.

Clinicians are invited to take part **in either or both** of the above research elements, and participation is completely voluntary.

¹ Scottish Government (2023) <u>Updated Guidance on the Implementation of Benefits</u>
<u>Assessment under Special Rules in Scotland (BASRIS) Guidance and form for Terminal Illness,</u>
for Disability Benefits devolved to Scotland



If you are willing to share your views and experiences of Special Rules for Terminal Illness via the survey, you can access it via this link:

- https://www.smartsurvey.co.uk/s/SpecialRules/ or
- by scanning the QR code:



The survey invites you to add your contact details at the end if you are willing to also take part in a follow-up telephone interview.

Alternatively, if you would prefer to take part in an **interview only**, please contact the lead researcher, Kate Skellington Orr, to find out more and to arrange a time to speak:

- by telephone: 01355 301399 or
- by email: kate@ksoresearch.co.uk

What we will do with the information you provide

Any personal information, like the contact details given to us to arrange the interview, will be held according to the General Data Protection Regulation (GDPR). This means that it will be kept completely confidential and will not be shared with anyone outside of the research team. All personal information will be deleted at the end of the project.

With your permission, we would like to record the interview using a digital voice recorder. Anything you say will be treated anonymously - it will not be linked back to you and no one (except the research team) will know that you have taken part in the work (except if there is a threat of harm to yourself or others, in which case we would need to act upon that information). We will never use your name or any of your personal details in reporting our findings from this work. Information you have told us will never be reported in a way that can reveal your identity.

If you are willing for us to record the discussion, we will use the recording to write up your feedback (using an independent transcriber) and we will then securely, confidentially and permanently destroy the recording. Only the research team will listen to the recording and it will not be kept by us for any longer than is necessary to complete the project.



Your feedback, including detailed anonymised notes and quotes from the interview, will be shared with the Scottish Government at the end of the research but, again, any personal data that you provide will be deleted from those. The Scottish Government may retain the anonymised feedback for the purposes of longer-term and wider review of the impact of devolved disability benefits in Scotland.

The Data Privacy Notice for this research can be found at:

SRTI-ClinicianPrivacyNotice-KSO

Anonymous findings from this work may be published by the Scottish Government and will primarily be used by them and Social Security Scotland to help inform the future development of SRTI and wider devolved disability benefits in Scotland.

Who to contact if you would like more information

For any queries, further information or to discuss the research in more detail, please contact the lead researcher, Kate Skellington Orr:

by telephone: 01355 301399 or

• by email: <u>kate@ksoresearch.co.uk</u>

Thank you for taking the time to read through this information sheet and consider this important research project.