



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

Participant Information Sheet

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 Special Rules for Terminal Illness (SRTI).

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

What the evaluation is about

The Scottish Government is keen to hear from people who have had experience of applying for or receiving social security benefits following a terminal illness diagnosis. This will help them to deliver a social security system that is built around people's experiences, to ensure that the system works for the people of Scotland, based on the principles of dignity, fairness and respect.

For this reason, they have asked an independent research organisation (KSO Research) to speak directly with people who receive any of the above disability benefits and who are living with a terminal illness. They would like to ask about your experience of applying for and receiving the benefit.

What taking part involves

If you are interested in taking part, a member of the research team will arrange a time to speak with you. You can have a friend or family member with you during the interview if you would like. If you are a parent, carer or appointee of a child or adult who receives disability benefits through Special Rules for Terminal Illness, then he or she would be welcome to join the conversation as well.

The researchers would like to speak with people either by telephone or online using Microsoft Teams or Zoom (whichever you prefer), and the discussions will



last around 30 minutes. Please let the research team know if you have any accessibility needs or require further support to take part in an interview. Interviews will be taking place between January 2025 and March 2025. Questions in the interview will cover areas such as your experience of applying for disability benefits, whether you applied using the Special Rules for Terminal Illness route, what you think is working well, and what could be improved. It will not cost you anything to take part - the researchers will call you directly. After the interview, they will send you a £35 'Love2Shop' voucher to thank you for your time.

Taking part is completely voluntary and your decision to take part, (including if you change your mind and wish to stop at any time), will not influence any decisions about you or your family's entitlement to any social security benefits, now or in the future. The research is completely separate from such decisions.

What we will do with the information you tell us

Any personal information that you give to us, like your contact details, 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. The only exception is if we hear anything during our conversation which makes us worried that you or someone else might be in danger of harm. In this case, we might have to inform relevant agencies. We will tell you if there is any information we need to pass on to other agencies. All personal information will be deleted at the end of the project.

With your permission, we would like to digitally voice record the discussion. Anything you say will be treated anonymously - it will not be linked back to you and no one (except the researchers) will know that you have taken part in the work. 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 form 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 and we will then securely, confidentially and permanently destroy the recording. Only the researchers will listen to the recording and it will not be kept by us for any longer than is necessary to complete the project.



If you do not want us to record the conversation, we will take handwritten notes, which will be typed up without your name after the conversation. The handwritten notes will be destroyed, and the typed version deleted at the end of the study or before if no longer needed.

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 will retain the anonymised feedback until December 2026, when the evaluation strategy is due to have completed.

We might use some things you say in the report we write for the Scottish Government, and these may also be used in the final Scottish Government report for this evaluation. Findings from the research will be published, and direct quotes from what you say may be used in the report. However, we will ensure that these quotes are fully anonymised and will not attribute anything to you by name.

Who to contact if you want to take part

If you would like to take part, please contact the lead researcher, Kate Skellington Orr, to find out more and to arrange a time to speak:

Telephone: 01355 301399

Email: kate@ksoresearch.co.uk

Post: KSO Research, Radleigh House, 1 Golf Road, Glasgow, G76 7HU

What to do if you have a complaint or any questions about the evaluation

If you have any concerns about the study or the conduct of the study team, or if you have any questions or want to discuss any information on this sheet, please don't hesitate to contact Kate at KSO (kate@ksoresearch.co.uk or 01355 301399)

Further Information and Advice

If you would like further information about disability assistance following a terminal illness, please visit [Social Security Scotland - Special Rules for Terminal Illness Frequently asked questions](#) or contact [Citizens Advice](#).



If you would like any further support following your participation in this research, please let the researchers know and they will be pleased to signpost you to a relevant support organisation.

Thank you for taking the time to read this information.