

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

## **Privacy Notice: Clients and Representatives**

**For the purposes of this project we collect and process the following information:**

- Name (for arranging an interview);
- Personal Telephone number (for arranging an interview);
- Email (for arranging an interview);
- Postal address (optional) - used only if you would like to receive a posted Love2Shop voucher instead of a digital voucher;
- Views and experiences of applying for and/or receiving Adult Disability Payments (ADP), Child Disability Payments (CDP) and/or Pension Age Disability Payments (PADP);
- Views and experiences of the impact of Special Rules for Terminal Illness on you/your family; and
- Demographic data (age, gender, ethnicity, postcode, and complexity of disability) (optional for summarising in the final report to highlight the variety of voices that the evaluation represents)

### **How we get the information and why we have it:**

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 policy changes to Special Rules for Terminal Illness (SRTI) have been experienced by individuals living with a terminal illness (or their representatives), and to assess whether the introduction of SRTI is meeting its policy commitments.

The Scottish Government is responsible for all personal data collected from you for this research (i.e. they are the data controller).

The research is being undertaken by KSO Research. They are responsible for collecting and processing all data related to this project (i.e. they are the data processor). They work under clear instructions on how your data will be processed and secured.

### **KSO Research Project Manager**

Kate Skellington Orr  
Radleigh House  
1 Golf Road  
Glasgow, G76 7HU  
kate@ksoresearch.co.uk

## **Why do we need to collect this information?**

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).

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.

## **Our lawful basis for processing:**

Under The Data Protection Act 2018 and following the General Data Protection Regulation, the lawful basis for processing this information is Article 6 (1)(e) "processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller" and Article 9 (2) (g) "for reasons of substantial public interest".

## **What happens to the information you provide?**

Your answers are treated with care and with full respect for your privacy.

Any personal information that you give to us, like your contact details, will be handled 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.

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. Where consent is given for us to voice record research interviews, we will use the recording to write up your feedback and we will then securely, confidentially and permanently destroy the recording. Only the research team members will listen to the recording and it will not be kept by us for any longer than is necessary to complete the project.

Where consent is not given for us to record research interviews, 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.

### **How long is your information stored for?**

The project consists of a number of elements, of which interviews are one part. It began in December 2024 and will run until April 2025. Your personal (and research) information will be kept for the duration of the project and all data will be destroyed by the researchers within 3 months of completion. The Scottish Government will retain the anonymised feedback until December 2026, when the evaluation strategy is due to have completed.

### **Your data protection rights:**

Under data protection law, you have rights, including:

- **Your right of access** - You have the right to ask us for copies of your personal information.
- **Your right to rectification** - You have the right to ask us to rectify information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.
- **Your right to restriction of processing** - You have the right to ask us to restrict the processing of your information in certain circumstances.
- **Your right to object to processing** - You have the the right to object to the processing of your personal data in certain circumstances.

You are not required to pay any charge for exercising your rights. If you make a request, we have **one month** to respond to you.

### **How to Contact Us:**

For more information about how your data is used you can contact us.

#### **Project Manager**

Dr Stefania Pagani  
Scottish Government  
Social Security Analysis, Forecasting, and Evaluation  
Communities Analysis Division  
2H North Victoria Quay  
Edinburgh, EH6 6QQ  
Stefania.Pagani@gov.scot

**Data Protection Officer**

Directorate for Internal Audit & Assurance  
Scottish Government  
3D North, Victoria Quay  
Edinburgh  
EH6 6QQ  
DataProtectionOfficer@gov.scot

**How to complain:**

You can also complain to the ICO if you are unhappy with how we have used your data. The ICO's address is:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF  
Helpline number: 0303 123 1113