



Information Sheet

Background

The Scottish Government is becoming responsible for some of the benefits previously delivered by the Department for Work and Pensions (DWP), including:

- Personal Independence Payment (PIP)
- Disability Living Allowance (DLA) for Children
- Carers Allowance
- Attendance Allowance (AA)

This means that some of the benefits that have historically been delivered by DWP, will soon be delivered by Social Security Scotland.

As part of the work to prepare for this change, the Scottish Government set up the Social Security Experience Panels. The Experience Panels are made up of over 2,000 people from across Scotland who have recent experience of at least one of the benefits being devolved to Scotland.

The Scottish Government is working with Experience Panel members to design a new 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. While the panel has a diverse membership, the Scottish Government is keen to ensure that seldom heard groups are included in the research, including those who have experienced the social security system following a terminal illness diagnosis and/or following the death of a loved one:

Link: <https://www.gov.scot/policies/social-security/engagement-on-social-security/>

The Research Project

For this reason, they have asked an independent research organisation (KSO Research) to speak directly with people who have experienced the social security system following a terminal illness diagnosis and/or following the death of a loved one.

The researchers would like to speak with people either alone, or in a small group, and the discussions will last around 60-90 minutes.

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/your family's entitlement to any social security benefits. The research is completely independent from such decisions.

You would be welcome to bring a carer or supporter with you, and we can reimburse any travel or other reasonable expenses that you incur. The researchers would also like to give you a £20 voucher to thank you for your time.

What we will do with the information you tell us

Any personal information, like your contact details that you have given to us, 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 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.

Who to contact if you want to take part

If you would be willing to meet with a researcher from KSO Research to share your views and experiences of social security benefits following a terminal illness diagnosis and/or the death of a loved one, please contact the lead researcher, Kate Skellington Orr, to find out more and to arrange a time to meet:

Telephone: 01355 301399

Email: kate@ksoresearch.co.uk

If you do decide to take part, the feedback will be used by the Scottish Government and Social Security Scotland to help them build a new system in Scotland that puts people first and makes a lasting difference to the lives of people who have similar experiences to you.

Thank you