



Privacy Notice

Personal Social Services: Survey of Adult Carers in England (SACE)

The Survey of Adult Carers in England (SACE) exists in a national policy context in which increasing consideration has been given to the role of carers.

In 2008 the government introduced the national carers strategy, concerned with the provision of support to ensure carers’ financial, mental and physical wellbeing. The strategy moved towards focusing on the capacity of carers to fulfil their educational and employment potential; to recognise themselves as carers; to have a family and community life; and as expert care givers, to be involved in designing care provision at a local and individual level.

In 2014 the Care Act put carers on an equal footing with the people they care for. It allows for provisions such as simplifying assessments, giving carers a legal right to support if they are eligible and setting the minimum level at which carers become eligible for support. The Act consolidates past legislation and regulation and aims for greater transparency, accountability and personalisation in health and social care.

What information does the SACE collect about me?

As a *Council with Adult Social Services Responsibilities (CASSR)* with an eligible population of at least 150 carers, Cumbria County Council is required to carry out this biennial survey. As part of the SACE the council will collect the following:

<i>Personal Data</i>	<i>Special Category Data</i>
<ul style="list-style-type: none"> Age 	<ul style="list-style-type: none"> Gender Ethnicity Sexual Orientation Religion Health: Method of Assessment, Carer Support, Funding Status, Long-Term Support Delivery Mechanism, Reported Health Condition, Use of Advocacy Services, Use of Interpreter/Translation Services

How is your personal data collected?

SACE provides outcome-focused intelligence information on carers and the services they receive. It measures the extent to which services improve carers’ ability to care and live a life outside the caring role. The need to assess the impact on carers of the provision and quality of services provided to service users is also important.

A unique code will need to be generated by councils so that returned questionnaires can be mapped back to the participant. This will enable survey teams to follow up those who have not initially responded to the survey, and to bring together information from a variety of data sources.

Data Sharing

The data collected are sent to NHS Digital and are used as the basis of analyses that are included in national level Official Statistics reports. Data are also used to populate several measures in the Adult Social Care Outcomes Framework (ASCOF).

The council may need to share your information without seeking your permission if:

- it is a legal requirement (in line with the Care Act 2014)
- there is a serious risk to you or to the adult you care for
- there is a good reason to share your information, e.g. a serious crime has been committed.

How will we use information about you?

Data collected via the SACE will be used to:

- inform and support policy and decision making at local/national level;
- improve care, services and outcomes for local populations;
- help carers make better choices about their support

Where personal or special category data is being processed the council must have a legal basis for doing so under either Article 6 or Article 9 of the GDPR.

Personal Data

- **GDPR Article 6(1)(c)** processing is necessary for compliance with a legal obligation to which the controller is subject (see *Applicable Legislation* below), and
- **GDPR 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

Special Category Data

- **GDPR Article 9(2)(b)** processing is necessary for the purposes of carrying out the obligations and exercising specific rights of the controller or of the data subject in the field of employment and social security and social protection law

Relevant Legislation

- Care Act (2014)

Data Security

It is essential that the confidentiality of participating carers is assured. Council staff, other than those administering the survey, cannot know whether individuals have completed a questionnaire or how questions were answered. The questionnaires, covering and reminder letters all contain assurances of confidentiality.

For this reason, access to the list of carers' details used to send out the questionnaire will be strictly controlled. Computer files will be password protected and/or stored on a secure server, and access to these will be restricted to those involved in mailing out the questionnaire and responsible for either pre-coding the questionnaires or setting up codes for the analysis. Questionnaires will be posted out to individuals. Completed questionnaires will be stored securely in locked cabinets.

Data Retention

In accordance with NHS guidance the council must retain paper copies of questionnaires until the publication of the final SACE report. After this point the council may retain copies if participants are

likely to take part in any follow up studies, otherwise electronic and paper versions will be deleted in accordance with the council's Retention and Disposal Schedule.

Feedback

The council will exercise its discretion if it receives responses that indicate that a carer may be at risk. Contact will be made with the respondent in the first instance to check whether they are happy for their comments to be passed on to an appropriate member of staff for consideration. Initial contact should not be made by a social worker or the person's care worker. Once consent has been obtained the council will follow local protocol for dealing with the issues raised.

Your Rights

You have the right to:

- request a copy of your records;
- request that your records be corrected if they are wrong; and
- request that your information is changed/removed if this is causing you harm/serious distress.

You can find further information in 'Your Rights': <https://www.cumbria.gov.uk/admin/privacy.asp>

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