

## Scottish Cancer Patient Experience Survey 2018

### Sampling Methodology

The Scottish Cancer Patient Experience Survey (SCPES) is a national postal survey which is jointly funded by the Scottish Government and Macmillan Cancer Support, and is run in partnership with Information Services Division (ISD, part of NHS National Services Scotland). The survey asks about patients' experience of their Cancer care journey, from thinking that something might be wrong with them to the support they received after diagnosis and treatment.

The sampling will be carried out by ISD and will be designed to:

- Provide results at national, NHS Board, Regional Cancer Network and Cancer Centre levels;
- Provide feedback relating to recent experiences;
- Include people who had experienced the range of cancer care services; and
- Minimise the chances of sending the survey to individuals that did not have cancer or who had died since leaving hospital.

ISD will use a national dataset containing records of acute hospital activity (SMR01) to identify those aged 16 or over with an inpatient or day case record with any mention of cancer between 1<sup>st</sup> January 2017 and 30<sup>th</sup> September 2017.

The following patients will be excluded from the sample:

- Patients who are known to be deceased.
- Privately funded patients receiving care in NHS or private hospitals.
- Patients treated in a private hospital/hospice.
- Scottish NHS patients treated in hospitals outside of Scotland but whose care was commissioned by an NHS Board.
- Patients who were not resident in Scotland.
- Patients who stayed in hospital for termination of pregnancy and/or conditions relating to pregnancy and childbirth.
- Patients who stayed in a hospital maternity unit.
- Patients who were resident in a long-stay hospital.
- Patients who were being treated for a mental health condition in a mental illness hospital.
- Patients who were being treated in a learning disabilities unit.
- Patients with an ICD10 code of C44 and all other C44 classifications (non-melanoma skin cancers).
- Patients with an ICD10 code of C84 and all other C84 classifications (rare haematological cancers with complex clinical definitions).
- Patients with an ICD10 code of D05 and all other D05 classifications (in situ breast cancers).

In order to confirm the diagnosis of cancer, and to minimise the risk of sending surveys to patients who did not have cancer, validation will be completed using the Scottish Cancer Registry (SMR6). Individuals who were identified from the hospital records **but do not have** a Scottish Cancer Registry diagnosis date between 1<sup>st</sup> July 2016 and 31<sup>st</sup> March 2017 will be excluded from the sample.

Once the list of eligible patients has been compiled, ISD will eliminate any duplications or incomplete records to determine the final sample frame. To ensure a sufficiently large response to the survey, a census approach will be taken.

This approach is consistent with the sampling methodology used in the 2015 survey, with one additional exclusion – those with an ICD10 code of D05. This change has been made following feedback from the 2015 survey which showed that, due to the variation in clinical definition of these types of tumours, a high proportion of helpline calls querying diagnosis were from individuals with this type of tumour. This could lead to distress / anxiety for these individuals and so it has been agreed that this tumour type should be excluded from future surveys.

Using the same sampling methodology between surveys will ensure a consistent approach and allows for robust comparisons over time.

More information on the survey can be found at [www.gov.scot/CancerSurvey](http://www.gov.scot/CancerSurvey).

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