

Written question on notice from Senator Catryna Bilyk

As you may be aware, on 29 November 2016 the Senate established a select committee to be known as the Select Committee into Funding for Research into Cancers with Low Survival Rates to inquire and report on the impact of health research funding models on the availability of funding for research into cancers with low survival rates, with particular reference to:

- a) the current National Health and Medical Research Council funding model, which favours funding for types of cancer that attract more non-government funding, and the need to ensure the funding model enables the provision of funding research into brain cancers and other low survival rate cancers;
- b) the obstacles to running clinical trials for brain cancers and other cancers with relatively lower rates of incidence, with regard to:
 - i) funding models that could better support much-needed clinical trials, and
 - ii) funding support for campaigns designed to raise awareness of the need for further research, including clinical trials;
- c) the low survival rate for brain cancers, lack of significant improvement in survival rates, and strategies that could be implemented to improve survival rates and;
- d) other relevant matters.

The Chair of the committee, Senator Bilyk, asks the Australian Charities and Not-for-profits Commission (ACNC) to provide a breakdown of government and private funding to cancer charities and not-for-profits by year from 2007 to 2017 (to date), based on their disclosures to the ACNC.

Answer:

Thank you for contacting the ACNC, we are grateful for the opportunity to provide information to this important Committee.

Unfortunately the ACNC is not able to provide a full response to the Senator's request. There are a number of reasons for this:

Establishment of the ACNC

The ACNC was established in December 2012, and the ACNC Act only required registered charities to provide financial information as part of their 2014 Annual Information Statement. This means that the ACNC does not have financial information about charities before the beginning of their 2014 financial year (in most cases from 1 July 2013).

Charities and not-for-profits

The ACNC currently only regulates registered charities, of which there are just over 54,000. There are an additional (estimated) 500,000 not-for-profit organisations in Australia which are not regulated by the ACNC, and for which the ACNC does not hold any information.

Funding to cancer charities

The ACNC collects financial information from registered charities each year in the Annual Information Statement and annual financial reports (for medium and large size charities – those with annual revenue of \$250,000 or over). The ACNC is able to provide a breakdown of government grants, and donations and bequests, for each charity, or at the aggregate level. A limitation, however, is identifying which charities undertake cancer research.

‘Cancer research’ is not a listed activity in the Annual Information Statement, therefore the ACNC is not able to provide a funding breakdown for charities that undertake or support cancer research specifically.

The ACNC can provide a breakdown of government and private funding (since 2014) for registered charities that have ‘cancer research’ either in their charity name, or in the summary of activities section of the Annual Information Statement. However, this will likely exclude many relevant charities and significantly underestimate the number of charities that undertake cancer research, or contribute charitable funds or assets to cancer research.

Similarly, the ACNC data is not able to determine what percentage of either government or private funds were attributed to cancer research. For example, some registered charities may provide grants for cancer research in addition to providing carers for those suffering from cancer.