



Gynaecological Cancers Data Management Project

The development of a nationally consistent approach to the collection and reporting of gynaecological cancer data for comparative analysis and benchmarking aims to improved clinical outcomes for all women affected by gynaecological cancers.

The National Centre for Gynaecological Cancers (the Centre) in partnership with the National Breast and Ovarian Cancer Centre (NBOCC) has commissioned CSIRO's Australian E-Health Research Centre to undertake two elements of work with the assistance of a project working group and the Centre's Advisory group.

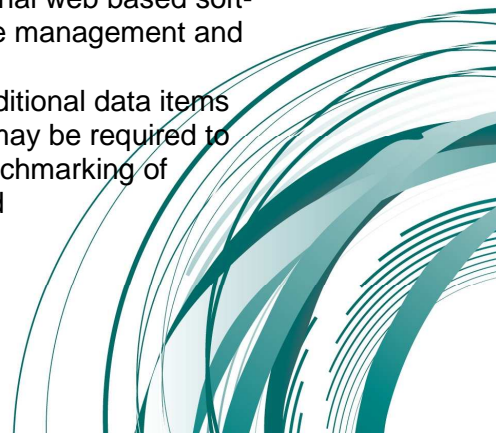
The first element of work includes:

- pilot testing the *clinical data set (CDS) for gynaecological cancers* in a number of locations around the country to ensure that the data dictionary definitions are accurately reflecting the data as intended and determining whether the data items are consistently and accurately collected;
- consulting with gynaecologic oncologists, hospital-based data managers and Health Department representatives, to identify what gynaecological cancer data items are currently being collected and what would be the barriers to collecting the data items identified in the gynaecological cancer clinical data set nationally; and
- utilising an appropriate means of collecting pilot site data e.g. a paper based or web based system for collecting national gynaecological cancer data and making recommendations about a national collection method that will reduce the burden of data collection on clinicians.

The **aim** is to develop an agreed practice ready National Clinical Data Set and data dictionary for gynaecological cancers ready for submission to the National Health Information Standards Committee.

The second element of work is a brief scoping study of existing current national and international surgical synoptic reporting frameworks and IT systems that may be used in the future to collect national gynaecological cancer data. This includes determining the feasibility and costs associated with developing/adapting and implementing a national surgical synoptic reporting system for gynaecological cancer outcomes in Australia. This will involve:

- the identification and assessment of existing web based data software solutions that allow national /or jurisdiction specific aggregation of **de-identified** data that can interface with local point of care reporting and data collection;
- the identification of barriers to the implementation of any national web based software reporting and data solutions, particularly in relation to the management and ownership of data;
- consultation with gynaecologic oncologists to identify what additional data items outside the specialist clinical gynaecological cancer data set may be required to allow national analysis of gynaecological cancer data and benchmarking of clinical outcomes for women with gynaecological cancers; and



- an estimate of the potential costs that would be required to develop and implement a national system including a brief cost benefit analysis to determine the value of the project to women affected by gynaecological cancers.

The **aim** of this element of work (developed at the request of gynaecological oncologists) is to scope the potential for a national synoptic reporting system for gynaecological cancers that may be used for benchmarking and quality assurance activities.

Background

In 2008, the Centre, in partnership with NBOCC, developed a clinical data set for gynaecological cancers to improve national consistency in data collection and benchmarking. Following advice from the Centre's Advisory Group, and building on the recommendations of the 2006 Senate Inquiry *'Breaking the Silence..'*ⁱⁱ, extensive consultation occurred with gynaecologic oncologists, cancer specialists, health professionals, state cancer registries, cancer councils, professional specialist organisations and consumer organisations to help inform the development of the Clinical Data Set (CDS) for gynaecological cancers.

The CDS for gynaecological cancers aims to compliment the data items collected under the Clinical Cancer Core Data Setⁱⁱⁱ. The 14 identified data items cover ovarian, cervical and endometrial cancers which represent the most common gynaecological cancers and are responsible for the most deaths from gynaecological cancers. The data items were developed to be compatible with data items developed by the International Federation of Gynecology and Obstetrics (FIGO). Definitions for each data item were developed in consultation with the sector.

ⁱ The National Centre for Gynaecological Cancers & the National Breast and Ovarian Cancer Centre: *Final Report Development of a Minimum Data Set for Gynaecological cancers*, June 2008. For more information on the Clinical Data Set (CDS) visit: www.gynaecancer.gov.au

ⁱⁱ In 2006 the Senate Community Affairs Committee conducted an inquiry into gynaecological cancers in Australia: *Breaking the silence: a national voice for gynaecological cancers*, in October 2006. You can read the report of the inquiry on the website of the Senate of Australia

ⁱⁱⁱ The Clinical Cancer Core Data Set was originally developed as the national generic minimum data set (MDS) under the aegis of the National Cancer Control Initiative (NCCI). Cancer Australia has subsequently assumed stewardship of this data set to ensure its currency and relevance. For more information on this and Cancer Australia's National Data Strategy visit: www.canceraustralia.gov.au

