

Online registry will help cancer patients preserve their fertility

January 14 2015, by Poppy Diamantis



In a world-first, the Randwick Hospitals Campus and UNSW Australia have launched an online registry that will capture a cancer patient's journey from diagnosis through to survivorship, and which can be used to help them plan for a family.

The Australasian Oncofertility Registry and website will collect international data from participating cancer and fertility centres about referrals to and uptake of fertility preservation in children, adolescents, young adults and adults; as well as collecting data on the fertility potential (ability to have a child) in cancer patients after diagnosis.

The Registry and website have been developed by the collaborative

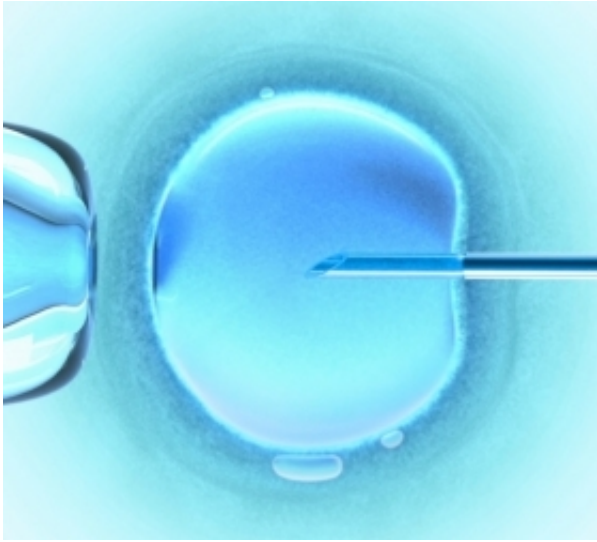
Fertility Understanding Through Registry and Evaluation (FUTuRE Fertility Research Group), based at UNSW and the Randwick Hospitals Campus – Prince of Wales Hospital, Royal Hospital for Women and Sydney Children's Hospital, Randwick.

The Group is led by Dr Antoinette Anazodo, Chief Investigator and Paediatric and Adolescent Cancer Specialist, Sydney Youth Cancer Service.

"Once a [cancer patient](#) finishes treatment, they may not be able to accurately recall the drugs or treatment received as a result of their diagnosis. As some cancer drugs can cause reproductive challenges, the Registry will be able to assist cancer patients and survivors by providing information at a later date when they choose to start their family," Dr Anazodo said.

Dr Anazodo said outcomes generated from the Registry will also assist cancer clinicians in providing accurate risk projections for a patient's future infertility after [cancer treatment](#).

"There is currently a major gap between acute cancer management and the implications for all patients' future fertility," she said



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"This collaboration will allow for the development of further opportunities to bridge the gap between cancer and fertility disciplines, and effectively communicate fertility preservation options and strategies to patients at the time of diagnosis and before starting treatment.

"Findings will also assist clinicians in providing accurate risk projections for future infertility and reproductive health following cancer treatment," she said.

UNSW Professor of Obstetrics and Gynaecology William Ledger, who is based at the Royal Hospital for Women, said barriers for fertility preservation and uptake may include a lack of standardised guidelines and referral pathways from cancer to fertility specialists.

"The difference in or lack of specialist advice, limited outcome data regarding safety and efficacy in cancer patients, fertility preservation costs and psychosocial distress are currently barriers for providing accurate fertility options to cancer patients," Professor Ledger said.

"This research via the Registry will lead to the development of evidence-based national guidelines surrounding the referral process from oncologist to fertility specialist. These standardised guidelines will have the potential to encourage continued collaboration between cancer and fertility specialists," he said.

One of the key aims of the Group, through the Registry, is to instil a best-practice model for cancer specialists to discuss the impact a [cancer diagnosis](#) or treatment can have on a patient's fertility and the options and strategies available to cancer patients for preserving their fertility.

In guiding the Registry, Dr Anazodo and her team have developed the first Australasian Oncofertility Charter with the input from adolescent, young adult and adult cancer patients and parents.

"This Charter outlines eight essential elements of 'gold standard' oncofertility care we are aspiring to achieve across Australia and New Zealand. Data from the Registry will help us track the progress in achieving these goals," Dr Anazodo said.

"It is the belief of all our patients and supporters that cancer patients should be given equitable access to pioneering [fertility preservation](#) techniques if appropriate, in the hope that they will one day be able to have a biological family."

The FUTuRE Fertility website is an informative resource centre for both cancer patients and health professionals interested in the area of oncofertility.

The website conveys detailed fertility and sexual health information sheets for cancer patients of all ages about what they may experience throughout their cancer journey, in order to make informed decisions about their reproductive and sexual health; as well as providing resources

and tools for [cancer](#) and reproductive health professionals.

More information: For more information about the work of the FUTuRE Fertility Research Group, see: www.futurefertility.com.au

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