



Health  
South Eastern Sydney  
Local Health District

# Media Release

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## **WORLD-FIRST AUSTRALASIAN ONCOFERTILITY REGISTRY AND DEVELOPMENT OF GUIDELINES TO IMPROVE ACCESS TO FERTILITY PRESERVATION FOR CANCER PATIENTS**

In a world-first, the Randwick Hospitals Campus and UNSW Australia have launched an online registry that will capture a cancer patient's fertility journey from diagnosis into survivorship, and provide a historical summary of their cancer and reproductive journey, which can be used to help cancer survivors plan for a family.

The Australasian Oncofertility Registry and website will collect international data from participating cancer and fertility centres on the referral 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 the Randwick Hospitals Campus - Prince of Wales Hospital, Royal Hospital for Women and Sydney Children's Hospital, Randwick - and UNSW.

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

"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.

Professor William Ledger, Professor of Obstetrics and Gynaecology, Royal Hospital for Women and UNSW Australia, 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 (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.

The Australasian Oncofertility Registry and website was made possible through the funding support of Salesforce, The Kids Cancer Centre, Fertility Society of Australia, CanTeen and Sydney Logos.

For more information about the work of the FUTuRE Fertility Research Group, see: [www.futurefertility.com.au](http://www.futurefertility.com.au) or [www.futurefertility.co.nz](http://www.futurefertility.co.nz) or follow the group on Twitter via: ANZOncofert Registry @ANZoncofert

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