

Social media cues for rare cancer clues

AUSTRALIAN researchers have turned to social media to learn more about the experiences of people who have been diagnosed with a rare form of ovarian cancer.

Specialists from the Hudson Institute of Medical Research - including researchers from Monash and Deakin Universities - have turned to an international Facebook group to learn about the experiences of women who have been treated for granulosa cell tumours (GCT).

A total of 743 members of the group, named GCT-Survivor Sisters, shared their treatment experiences.

The study was designed to give a voice to patients who often don't feel heard by the medical profession.

Deakin University's Victoria White, who was lead author of the resulting paper, said there was a growing push for people with lived experiences to play guiding roles in research.

She said being able to access the database that had been developed through the survivors' group and then



Sue Rodgers took part in a new research project aimed at improving treatment options for people with a rare form of ovarian cancer. Picture supplied

working with members... "has been a terrific experience and helps to ensure the issues consumers want to see addressed are recognised".

US-based member Sue Rodgers said the Facebook group had been trying for many years to bring attention to the rare disease. When Hudson Institute researcher Maria Alexiadis reached out, a wonderful relationship was formed.

"Social media has played an extremely important part in sharing effective cancer treatments... and educating people to advocate for themselves with their physicians," Ms Rodgers said.

Ms Alexiadis said there was a lack of clinical evidence of efficacy of treatments for the form of cancer due to its rarity.

"There's even a lot of uncertainty about chemotherapy and limited evidence regarding its benefit for both early and advanced stage of this disease," she said.

Granulosa cell tumours are rare, making up 2-7 per cent of malignant ovarian cancers.

They can develop at any age.

The condition has a high rate of late recurrence in those who are successfully treated.