

Importance of engaging with consumers, in health and medical research

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Consumer and community engagement

UK - University College London (2001- 2010)

- Laboratory tours monthly to consumers & family members
- Lay seminars for ovarian cancer charity (Christies London)



USA – University of Southern California (2010 - 2016)

- monthly seminars attended by consumers



Australia – University of New South Wales (2016 - current)

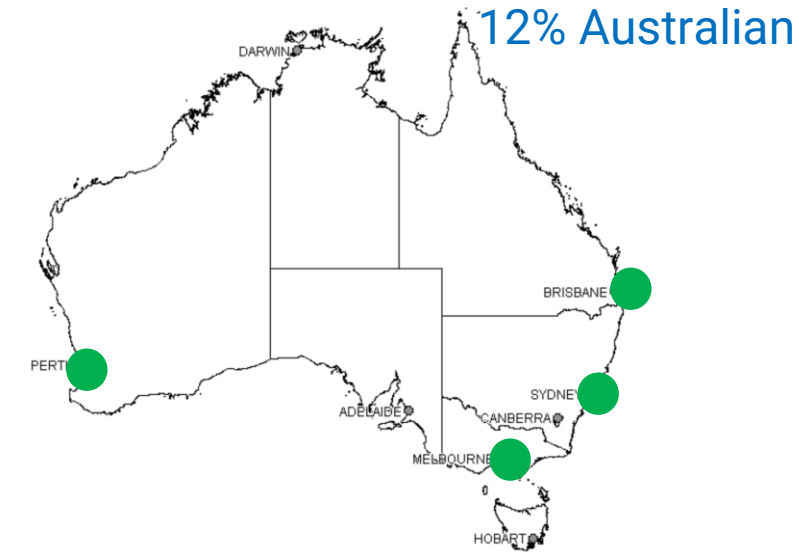
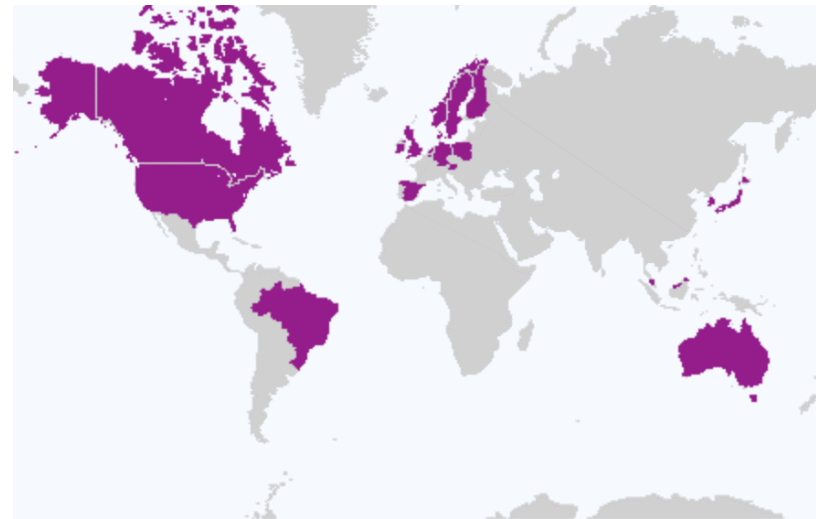
- Consumers from Cancer Voices (& TCRN) involved in all projects

International consortium (2012 - current)

- Consumer input into all projects



OCAC & OTTA consortium



OCAC: 82 studies: 30 USA, 7 Canada, 8 UK, 24 Europe, 7 Asia, 1 South America, 5 Australia
OTTA: 71 studies: 26 USA, 8 Canada, 10 UK, 19 Europe, 3 Asia, 1 South America, 4 Australia

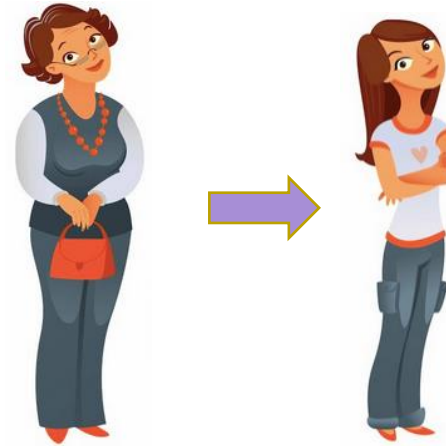
Ovarian cancer: Improving outcomes

Can we identify patients earlier?

Genetic studies

Risk prediction > Prevention

Impact for family members



Can we improve treatments?

Tumour studies

Prognostic markers and signatures

Changes to treatment decisions



Molecular Oncology Group (2016-now)

Consumers – lab projects



Consumers – International projects



Cindy, Anne, Bronwyn & Jean

Gill & Jacinta

Images of consumers removed at presenter's request

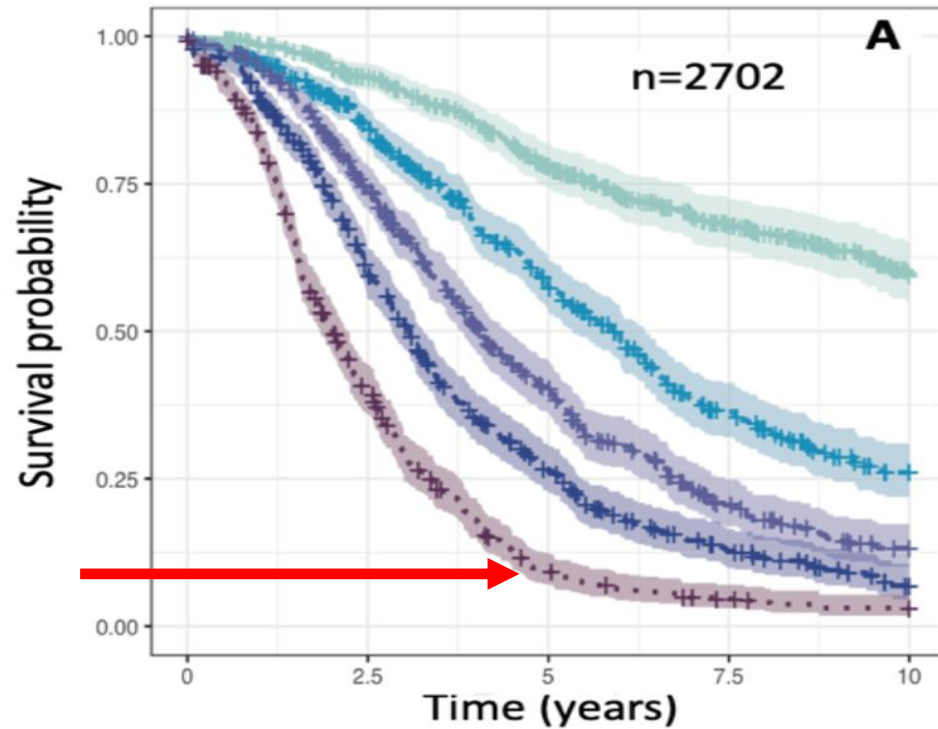
Jenni

Daria

Chris

Direction of projects – what patients are interested in, less invasive tests
Distribution of results to network and community

Prospective validation OTTA SPOT



800 prospective cases over 2 years

Would patients want to have a test at diagnosis that could indicate prognosis?

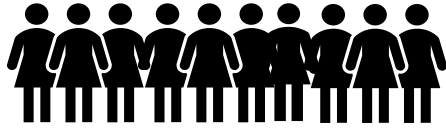
What alternative treatments would be available?

How would they like the results presented?

Patient acceptability study



Co-design



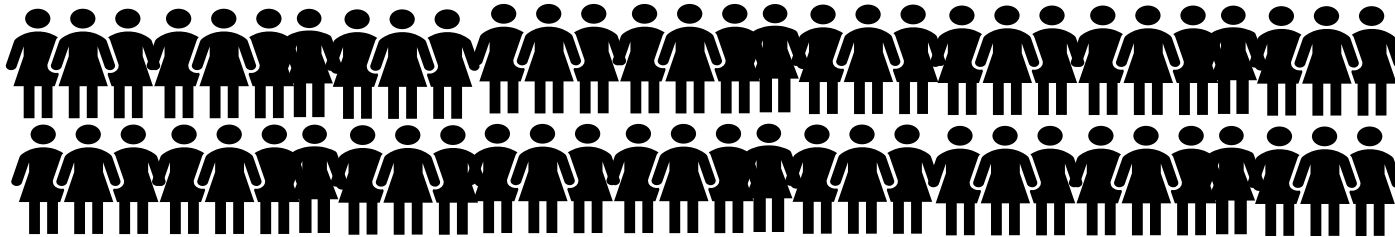
Focus group



Co-design



Ethics approval



Study

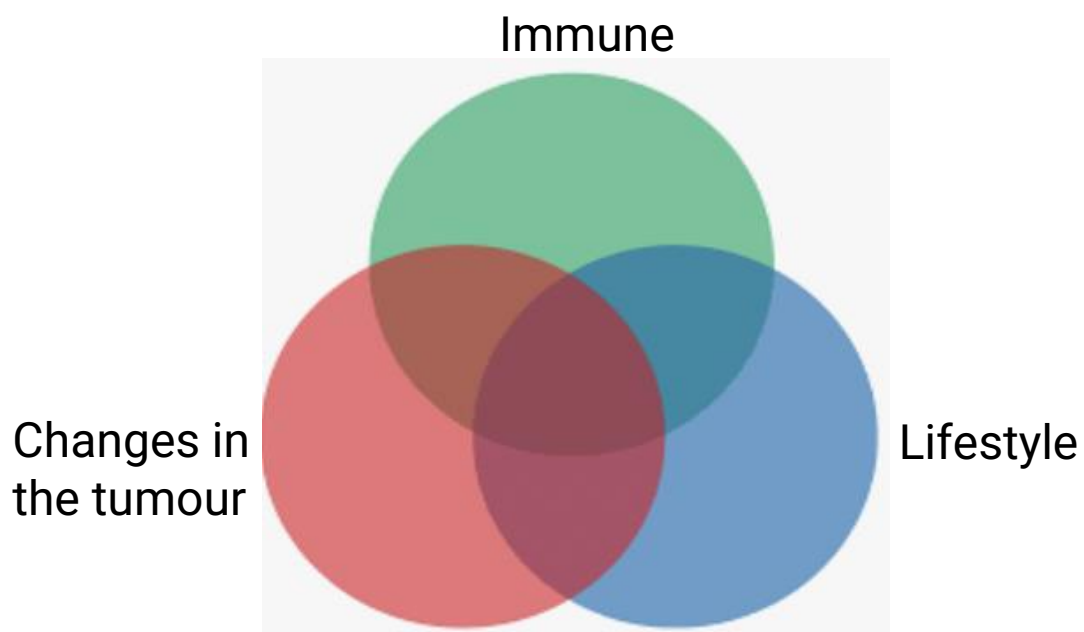




Long term survivors - MOCOOG

Long term survivors 10+ years survival - 1,800 cases

Compared to short and medium – 1,800 cases each - matched



Consumer initiated project

Why do some women survive more than 10 years?

Funding for consumers to attend meetings

International Consortium



Cancer Voices

Cancer Voices website.

Helps others to learn how a successful partnership can work and what each partner can bring to the relationship.

The screenshot shows the Cancer Voices NSW website. At the top left is the logo with a green speech bubble icon containing a white 'C' and the text 'cancer voices nsw'. The navigation menu includes 'Home', 'About', 'Get Involved' (underlined), 'News', and 'Contact'. A search icon and a 'Donate' button are on the right. The main heading is 'Consumer Researcher Profiles' in green, with a breadcrumb 'Home / Consumer Researcher Profiles' below it. The sub-heading is 'Consumer Researcher Profiles' in green. The main text reads: 'Cancer Voices NSW consumers partner with researchers through our Consumer Involvement in Research (CIR) Program. Both the consumers and researchers bring something different and unique to the partnership and both gain from the interactions.' Below this is a paragraph: 'Meet some of our consumers and their researcher partners and read what they have to say about these partnerships, what motivates them and how they work together to support cancer research.' At the bottom, there is a 'View all' button and four partnership links: 'Partnership No. 4', 'Partnership No. 3', 'Partnership No. 2', and 'Partnership No. 1'. On the right side, there is a call to action box with the text 'Cancer Voices NSW is entirely dependent on donations to carry out our important work' and a 'Donate Now' button. Below that, another box shows the heading 'Consumer Researcher Profiles'.

Consumer thoughts

If you could say one thing to a new consumer representative, what would it be?

Don't be intimidated, researchers value your unique perspective.

A final word

Being a consumer has enriched my life in ways that I could never have anticipated. I like the challenge of a steep learning curve! Most survivors and carers haven't heard of consumers in research. It would be good if there were stories in mainstream media, to help us recruit a more diverse pool of consumers.

Consumer thoughts

If you could say one thing to a new consumer representative, what would it be?

It is a rewarding experience. Go for it if you can. Make your voice heard, it is very important.

You will also learn a lot in the process and will be able to relate to a lot of the research work.

A final word

An important role of the consumer representative is to help make the research work even more relevant and relatable to the real-life experiences of cancer patients and society in general.