

MI-CRE 2024 Annual Research Symposium and Policy Forum

Consumer Involvement Story

'Who is this for?' Involving consumers in ovarian cancer research

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Is Presenter an HDR Student? No.

Has Research been submitted/presented elsewhere: I presented some similar content at the Daffodil Centre 2024 annual symposium which had a focus on involving consumers in research.

Abstract

Working with an inspiring group of three consumer researchers with a lived experience of ovarian cancer has had a big impact on my research. Consumers help to frame the priorities and the questions that I ask, to put our work into context, and to support me to communicate my results in a meaningful way. Listening to the stories of our consumers is highly motivating, and they are not shy to hold me to account on the relevance of my work. This is a very humbling experience!

Ovarian cancer is a devastating disease, and up until recently has had a 'one-size-fits-all' approach to treatment. My work using the Medicines Intelligence Data Platform has been developed with consumer input from the beginning and will look at the use of a new targeted therapy treatment to help us understand its utilisation in the real world. It will also investigate whether there are sub-groups of patients with ovarian cancer who are not receiving the relevant genetic and tumour testing to assess their eligibility for these treatments based on demographic, comorbidity, or socio-economic factors. Our consumers are highly connected to their community of people with a lived experience of ovarian cancer and are passionate advocates for equity in access, especially for regional patients.