

The Key to Successfully Developing an Online Platform for those Impacted by a Gynaecological Cancer and or a Genetic Mutation: early Public and Patient Involvement and Engagement.

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Introduction

The importance of the patient voice is only recently recognised as being a key component in service improvement. Those who have a lived experience of a disease have a unique lens. Early use of patient and public involvement (PPI) ensures service improvement in areas that are useful to patients and clinicians. The PPI development of an online gynaecological oncology and cancer genetic platform is novel



Methodology

Participants with a diagnosis of a Cervical, Ovarian, Uterine, Vulva, Vaginal, BRCA and/or Lynch Syndrome genetic mutation were sought from within the Irish Society of Gynaecological Oncology PPI group, Lynch Syndrome Ireland, Ovacare, Placenta Accreta Ireland, Marie Keating BRAC support group and The Irish Coalition for People Living with Obesity in Ireland to guide the content of an online platform entitled thisisGO.ie.

Nine focused groups were held with between 4-6 persons in each group. Homework (to explore the current pathways on thisisGO.ie) was set prior to the workshop. Participants attended a 2-hour focused workshop which was recorded, transcribed, and qualitatively analysed via an interpretive phenomenological approach (IPA). Pre-screening of each phase was sent to the relevant PPI for feedback before it went online.

Affiliations

1. Living Well Cancer Programme, Catherine McAuley Research Centre, Mater Misericordiae University Hospital, Eccles Street, Dublin 7.
2. Irish Society of Gynaecological Oncology Patient and Public Involvement
3. UCD Gynaecological Oncology Group, Mater Misericordiae University Hospital, Eccles Street, Dublin 7
4. Department of Clinical Genetics, Royal Marsden Hospital, London, UK.

Results

Thematical content was identified to populate the pathway. Some areas identified were genetic testing pathways, implications for insurance, psychological response, management of uncertainty and how to communicate to family members. Having a reliable platform where one could get accurate information was identified as a comfort. Feelings of inclusiveness, particularly for the lynch syndrome and those living with obesity participants.



Conclusion

ThisisGO.ie launched in May 2021 it is hoped by October 2022 to be complete. It has been used by patients, family members and health care professionals. Evaluating the user experience of the platform is currently being explored



thisisGO.ie figures September 2022

64,021 page views

11,359 homepage

3,469 'Create profile' visits

626 profiles created

(19% conversion rate)

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