



Pilot study of an online training program to increase genetic literacy and communication skills in oncology healthcare professionals discussing *BRCA1/2* genetic testing with breast and ovarian cancer patients

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Received: 9 March 2021 / Accepted: 30 April 2021 / Published online: 10 May 2021
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Abstract

The increasing use of genetic testing for *BRCA1/2* and other pathogenic variants in the management of women with breast and ovarian cancer necessitates increased genetic literacy in oncology healthcare professionals. This pilot study aimed to evaluate an online training program to increase genetic literacy and communication skills in Australian oncology healthcare professionals tasked with discussing and coordinating mainstream genetic testing with breast and ovarian cancer patients. A training website with embedded videos was developed. This study assesses the website's acceptability and user-friendliness; suggestions for improvement were also elicited. Oncology healthcare professionals were recruited through relevant professional organisations, invited to the study by email, asked to work through the website and then complete an online questionnaire. Thirty-two oncology healthcare professionals completed the questionnaire after viewing the website. Nearly all participants were satisfied with the information contained in the program (very satisfied: $n = 14/32$, 44%, satisfied: $n = 17/32$, 53%, neither satisfied nor dissatisfied: $n = 1/32$, 3%) and reported that they had gained new skills ($n = 29/32$, 91%) and had increased confidence ($n = 29/31$, 94%) in communicating with breast and ovarian cancer patients about genetic testing. More than 93% ($28/30$) of participants endorsed the online program as clearly presented, informative, relevant and useful. This pilot study demonstrated high feasibility and acceptability of the training program to increase genetic literacy and communication skills in oncology healthcare professionals discussing genetic testing with breast and ovarian cancer patients. Further evidence from a randomised trial is needed to evaluate effects on changing clinical practice, improving patient outcomes, and cost-effectiveness.

Keywords Communication training · Online training · Oncology healthcare professionals · Genetic testing · *BRCA1* · *BRCA2* · Breast cancer · Ovarian cancer

Introduction

Germline testing of cancer susceptibility genes refers to testing for specific, high-penetrance pathogenic variants. This includes pathogenic variants in the breast/ovarian cancer genes *BRCA1* and *BRCA2* (*BRCA1/2*). Identification of carriers of these variants can save lives because it allows for: (i) identification of affected women who may benefit from targeted treatment options [1–3]; (ii) prevention of other

primary cancers; and (iii) the opportunity for predictive testing in biological relatives to enable implementation of preventative strategies in those identified as carriers [4–6].

Traditionally, genetic testing for cancer susceptibility and communication of the results have been managed exclusively through genetics-trained specialists at familial cancer clinics. In recent years, there has been a paradigm shift with the provision of genetic counselling and testing increasingly offered by non-genetics trained specialists, often referred to as 'mainstreaming'. This shift in practice benefits patients and their families through potentially increased and faster access to appropriate publicly funded germline genetic testing [7, 8].

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Several factors have prompted the adoption of a mainstreaming model of genetic testing. Australian [9] and international guidelines [10] on germline *BRCA1/2* genetic testing have expanded to include other indications in addition to the classic feature of a strong family history [11, 12], increasing the number of women for whom genetic testing is recommended. These additional indicators include younger age at breast cancer diagnosis, presence of bilateral breast cancer, membership in an ethnic group with a high incidence of founder mutations (for example, Ashkenazi Jewish background), as well as tumour tissue characteristics, in particular triple negative breast cancer (estrogen and progesterone receptor and HER2 negative) [11, 12]. Second, the availability of targeted treatment, poly (ADP-ribose) polymerase (PARP) inhibitor, for platinum-sensitive *BRCA*-mutated high-grade epithelial ovarian cancer patients [13] means that it is more time-efficient for oncology specialists to request these tests without needing to refer the patient to a specialised genetics clinic. *BRCA1/2* testing may also be of assistance in planning surgical therapy for women with breast cancer, whilst receiving neoadjuvant systemic therapy [14]. The falling costs of all types of genetic tests [15] have also contributed to the rapidly increasing number of tests ordered. Finally, in Australia one driver of a shift towards mainstreaming is the recent provision of government (Medicare) funding for germline testing of breast and ovarian cancer predisposition genes, which may be requested by a non-genetics specialist [13, 16].

Communicating germline genetic test results can be challenging, in particular, when variants of uncertain significance are found, or when no pathogenic variant is identified to explain a significant and penetrant family history suggestive of an underlying high-risk gene. Healthcare professionals obtaining consent for germline mutation analysis from patients face the challenge of counselling about possible outcomes to ensure informed choice. This requirement and the demands of addressing a shared family risk require skills in genetic literacy and in genetic risk communication.

Numerous overseas studies have shown that non-genetics healthcare professionals, including medical oncologists [17], have insufficient knowledge of genetics, are mostly ill-prepared to counsel patients regarding germline genetic test results and report unmet educational needs [18–21]. Similarly, a recent Australian needs assessment of medical specialists from diverse medical backgrounds highlights a need for continuing genomic education that is targeted to the speciality [22]. Non-genetics healthcare professionals are often poor at accurate and detailed family history documentation [8, 23] and risk communication [24] and reportedly lack adherence to guideline-based practices regarding *BRCA1/2* testing [25]. Finally, and possibly most importantly, misinterpretation of test results may result in incorrect management [19, 25]. Unless specialists receive education and

training in genetic literacy and communication skills, their genetic care of individual patients may be unhelpful and possibly even harmful.

Mainstream genetic testing differs from traditional genetic testing because it is treatment-focused—it has the potential to provide a treatment advantage to the individual. As such, most people want testing. In our previous studies in both the breast cancer and ovarian cancer setting, we demonstrated that women unanimously commented that the decision to undergo testing was a “no-brainer” [26–29]. As such, the communication skills required in the context of mainstream testing need to predominately focus on conveying genetic testing results to patients, in contrast to the communication skills required in relation to traditional genetic testing, which encompass tailored counselling to promote informed and shared decision-making regarding whether to have or postpone testing.

Genetic literacy and communications skills are a complementary set of proficiencies: *Genetic literacy* includes knowing the indications for having particular germline genetic tests and core concepts to understand genetic risk, while *communication skills* focus on skills for conveying complex and nuanced genetic testing results to patients and family members. Given the rapidly increasing number of genetic tests being offered by oncology healthcare professionals, there is an urgent need for the genetic literacy and communication skills of these professionals to be enhanced to ensure optimal translation of genetic research findings into mainstream healthcare [22, 30, 31]. A meta-analysis [32] and other reviews [33, 34] of online training interventions for specialists conclude that such interventions are educationally beneficial and can achieve outcomes similar to those of traditional teaching methods, with studies favouring online instructions compared to traditional methods [32]. Therefore, online training of oncology healthcare professionals seems particularly well suited to achieve the desired advances in genetic literacy and communication skills.

This article describes the development and pilot testing of an online training program to increase genetic literacy and communication skills to convey *BRCA1/2* genetic testing results in oncology healthcare professionals discussing genetic testing with breast and ovarian cancer patients. The focus of the website was on genetic testing for *BRCA1/2* pathogenic variants because of the rarity of pathogenic variants related to breast and/or ovarian cancer predisposition in other genes, and because at the time of the study targeted treatments covered by Medicare funding such as PARP inhibitors were only available for *BRCA1/2*-mutated platinum-sensitive relapsed high-grade serous epithelial ovarian cancer [1–3]. However, the online training module was always written with the intention of expanding it at a later time to include other genes—not just breast and ovarian cancer genes, but also bowel cancer and other genes.

Methods

Development of website content

The online training program was developed by a multidisciplinary committee, including healthcare professionals with expertise in genetic counselling, clinical genetics and oncology and an expert in healthcare communication. The website is available for viewing at the following URL: <https://www.mainstreamgenetictesting.com.au>.

The content of the website was based on a previously developed face-to-face workshop training module for oncology healthcare professionals to enable mainstreamed genetic testing [35]. This module in turn was informed by a formerly published mainstreaming training module [7], our previous research findings [28, 36], national guidelines regarding who was eligible for testing [9] and expert opinion.

Format of the website

The website was developed to meet the needs and demands of non-genetics specialist oncology healthcare professionals and to enable access to an online educational tool for use at anytime and anywhere. The website is built on the WordPress platform. It utilises the LearnDash learning management system (LMS) and contains two SCORM 2014-compliant/Tin Canny modules, developed using Articulate Storyline 360. The website contains two modules. Module 1 provides an introduction to mainstream genetic testing, and Module 2 covers the mainstream genetic testing process.

Embedded videos

Modules 1 and 2 include a total of eight embedded videos, which are arranged thematically throughout the modules and are between 0:38 and 4:00 min in length. They feature a genetic counsellor, an oncology nurse and a medical oncologist, who are well-known Australian and UK-based experts in *BRCA1/2* genetic testing.

Links to resources

Links to resources are provided to: the national guidelines on *BRCA1/2* genetic testing [9]; Medicare Benefits Schedule items to ensure correct ordering of tests [13, 16]; a list of local familial cancer clinics/genetics services; and a guide to using the Manchester scoring system to assess a patient's eligibility for genetic testing under the Medicare Benefits Schedule, adapted from Evans et al. [37]. Other tools and resources to support mainstream genetic testing were based on the developed face-to-face workshop training module for

oncology healthcare professionals to enable mainstreamed genetic testing [35]. These tools and resources included: a flow chart describing the mainstream genetic testing process, a patient consent form template, a genetic test request form template and a sample script to help guide the introduction of mainstream genetic testing to patients. Two patient education brochures are also included: (i) on *BRCA1/2* genetic testing in women newly diagnosed with ovarian cancer (developed as part of the previous workshop training [35]), and (ii) on treatment-focused genetic testing for women newly diagnosed with breast cancer [27]. Finally, a fact sheet on life insurance and genetic testing is included.

Content of the website

Module 1: introduction to mainstream genetic testing

Module 1 consists of 19 content screens covering: an introduction to mainstream genetic testing of *BRCA1/2*, fundamentals of genetics and an overview of genetic testing. The content screens are followed by reinforcing activities consisting of seven screens with open-ended, true/false questions and multiple-choice items. See Fig. 1 for examples of reinforcing activities. Instructions ask users to check their understanding of the information provided in the module by checking their answers against the summary screens following these reinforcing questions. Module 1 includes two summary screens.

Module 2: the mainstream genetic testing process

Module 2 consists of 34 content screens covering: tools and resources to support mainstream genetic testing of *BRCA1/2*; assessment that the patient meets the eligibility criteria for Medicare funded genetic testing; introduction to mainstream genetic testing, consenting patients for testing and organising the test; receiving, interpreting and giving genetic test results; referral to the local familial cancer clinic/genetic service; and questions patients are asked during the mainstream genetic testing process. The content screens are once again followed by reinforcing activities consisting of eight screens with questions, followed by three summary screens.

Evaluation of the communication skills and genetic literacy training program

Participants

Individuals were deemed eligible to participate if they were oncology healthcare professionals and provided care to oncology patients in Australia, including medical or radiation oncologists, gynae-oncologists, surgeons, and oncology nurses. These professional groups were included because

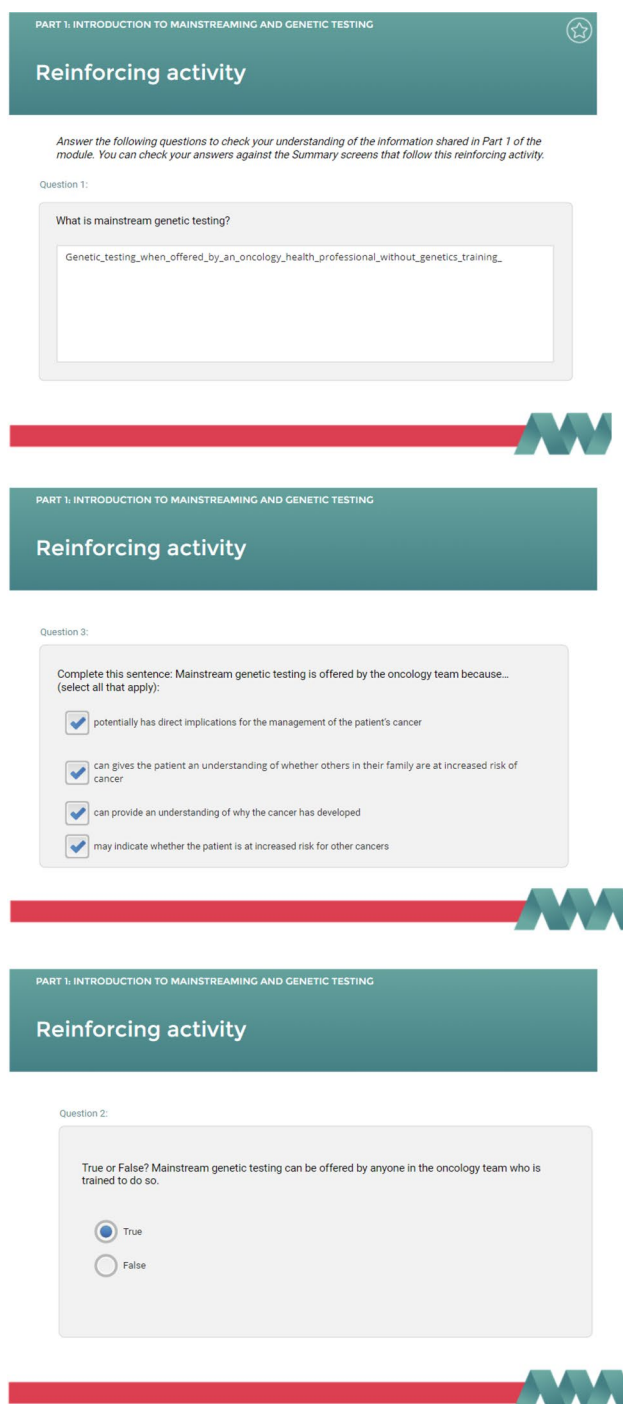


Fig. 1 Examples of reinforcing activities

they were either already discussing genetic and genomic testing with patients or were likely to do so in the future.

Recruitment

Oncology healthcare professionals were identified through relevant professional organisations: Clinical Oncological Society of Australia, Medical Oncology Group of Australia, Royal Australian and New Zealand College of Radiologists, Royal College of Surgeons and Cancer Nurses Society of Australia. Invitation emails were sent via these organisations or invitations were included in the organisations' newsletters. Interested healthcare professionals were directed to click on a link to access the training program, work through the website, access the link to the Participant Information and Consent form and then asked to immediately complete the survey. The online survey software Qualtrics was used to administer these surveys.

Measures

The online survey was adapted from a previously used survey instrument [38] (Supplementary File 1). It included the following measures:

Socio-demographic and professional details. Gender, age, professional background, work setting, length of practice in current field as well as current frequency of discussing genetic testing with patients were assessed.

Experience of using and satisfaction with the online program. Fifteen items with Likert-type and open-ended response options assessed: use of the program; preferences for length of program; satisfaction with different components of the website including: perceived relevance, usefulness and acceptability; and perceived helpfulness of program in terms of improving understanding and skills relating to communicating with breast and ovarian cancer patients about genetic testing. In addition, participants were asked to rate (using Likert-type response options) each of the two modules in terms of whether they were: clearly presented, informative, adequate, appropriate, relevant to their work, and useful to their work.

Self-rated competence in communicating with breast and ovarian cancer patients about genetic testing. Five items, adapted from two previous communication skills training studies [39], assessed self-rated competence in communicating with patients about genetic testing, using Likert-type response options anchored from 'Strongly disagree' to 'Strongly agree' (for example, 'Now that I have completed the training program, I feel confident in communicating with breast and ovarian cancer patients about genetic testing').

Data analysis

Data were analysed using the Statistical Program for the Social Sciences Version 25. Basic descriptive statistics, including means, medians, percentages, ranges and standard

deviations were calculated to describe the sample and responses.

Results

Socio-demographic and professional characteristics

Thirty-two individuals completed the questionnaire. Demographic and professional characteristics of participants are shown in Table 1. Fourteen (44%) were medical oncologists or medical oncology trainees, 1 (3%) was a gynaecologist, 5 (16%) were surgeons, 11 (34%) were nurses and 1 (3%) was an oncology pharmacist. Twenty-five (75%) were female. Five (16%) reported never discussing genetic testing with patients, nine (28%) discussed genetic testing 1–5 times a year, while five (16%) each discussed it 6 to 10 and 11–20 times a year, and 8 (25%) > 20 times a year.

Experience of using, and overall satisfaction with, the online program

All participants completed all sections of the program, and 75% completed it in one sitting. The time taken to complete the program varied, with three (9%) taking < 30 min, eight (25%) 31–45 min, 14 (44%) 46–60 min and seven (22%) 61–90 min. Thirty (94%) believed that the length of the online training program was about right, and two (6%) thought it was too short. Fourteen (44%) were very satisfied, and 17 (53%) were satisfied with the information contained in the program, while one (3%) was neither satisfied nor dissatisfied. Similarly, 8 (25%) of participants reported finding the program “extremely helpful”, 19 (59%) “very helpful” and five (16%) “satisfactory” in giving them an understanding of issues relating to communicating with breast and ovarian cancer patients about genetic testing. Twenty-nine (91%) stated that they gained new skills from the program relating to communicating with breast and ovarian cancer patients about genetic testing. Twenty-two (73%) percent believed that the videos in the program were useful in showing the issues related to genetic testing as experienced by oncology healthcare professionals, while one (3%) did not believe so and seven (23%) were unsure. Thirty participants (100%, disregarding two participants where data were missing) considered that the online format was appropriate for the program, that the additional resources contained in the training program were easily accessible, that the program was easy to use, and that they would recommend it to their professional colleagues.

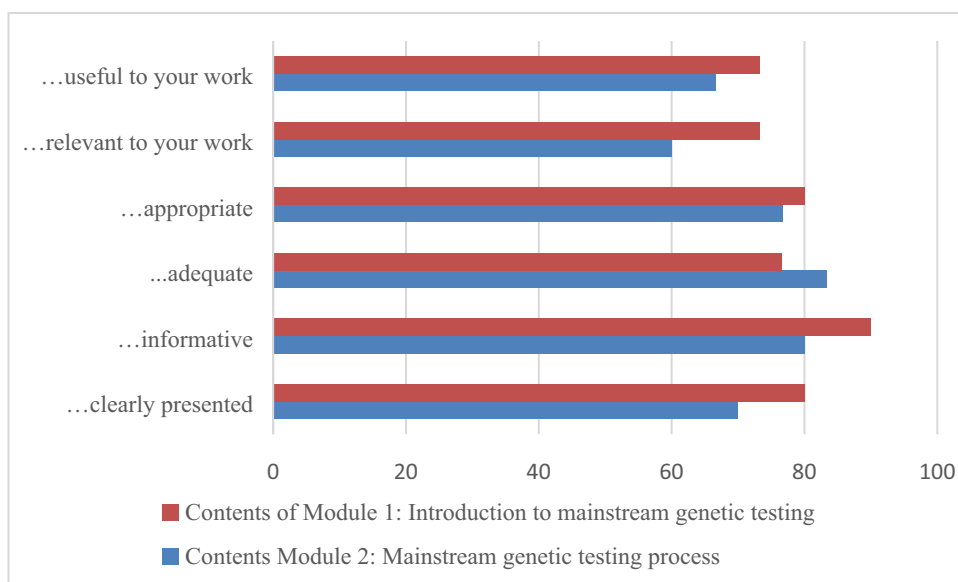
Table 1 Baseline characteristics of oncology healthcare professionals

Characteristics	(N=32) N (%)
Age (years)	
18–29	1 (3)
30–39	20 (62)
40–49	9 (28)
50–59	1 (3)
60+	1 (3)
Gender	
Female	24 (75)
Male	8 (25)
Professional background	
Medical oncologist	8 (25)
Medical oncologist trainee	6 (19)
Gynaecological oncologist	1 (3)
Surgeon	5 (16)
Nurse	11 (34)
Oncology pharmacist	1 (3)
Place of practice	
Metropolitan	25 (78)
Rural	5 (16)
Both	2 (6)
Public/Private sector practice	
Public	18 (56)
Private	9 (28)
Both	5 (16)
Years of practice in current field	
0–5	21 (66)
6–10	5 (16)
11–20	2 (6)
More than 20	4 (13)
How often do you discuss genetic testing with patients?	
Never	5 (16)
1–5 times a year	9 (28)
6–10 times a year	5 (16)
11–20 times a year	5 (16)
> 20 times a year	8 (25)

Satisfaction with the modules of the online program

Figure 2 displays the satisfaction with the modules of the online program. Between 70 and 90% of the participants thought that both modules were “very” clearly presented, informative, appropriate, relevant and useful for participants’ work, while between 10 and 33% provided an endorsement of “somewhat” regarding these attributes.

Fig. 2 Percentage of participants endorsing modules of training program as “very...



Self-rated competence in communicating with breast and ovarian cancer patients about genetic testing

Table 2 shows the responses to five items, which assessed self-rated competence in communicating with breast and ovarian cancer patients about genetic testing. For example, 19 (61%) of participants “somewhat agreed” and 10 (32%) “strongly agreed” they were confident in communicating with breast and ovarian cancer patients about genetic testing after they completed the program, while 2 (7%) “neither agreed nor disagreed”.

Suggestions for improvements

A number of participants made suggestions for improvements in response to open-ended questions related to several themes: (i) resources (e.g. offer additional links to gain more in-depth knowledge for those who are interested, provide the option of downloading slides or a summary of the training website); (ii) provide more opportunities for clinicians who are time poor (e.g. shorten the videos to enable those who are time poor to watch them); (iii) generalisability (e.g. offer more information about genetic testing in other contexts, for example *BRCA1/2*-positive pancreatic cancer, as well as other inherited conditions and provide training which targets pathogenic variants in genes other than *BRCA1/2*); (iv) practice/rehearsal (e.g. provide an opportunity to practice

Table 2 Self-rated competence in communicating with breast and ovarian cancer patients about genetic testing

Statement	Strongly disagree n (%)	Somewhat disagree n (%)	Neither agree nor disagree n (%)	Somewhat agree n (%)	Strongly agree n (%)
Before the training program, I felt confident communicating with breast and ovarian cancer patients about genetic testing	3 (10)	12 (39)	2 (6)	11 (35)	3 (10)
Now that I have completed the training programme, I feel confident in communicating with breast and ovarian cancer patients about genetic testing	0 (0)	0 (0)	2 (7)	19 (61)	10 (32)
I feel confident that I will use the skills I learned in the training program	1 (3)	0 (0)	3 (10)	13 (42)	14 (45)
The skills I learned in the training program will allow me to provide better patient care	0 (0)	0 (0)	0 (0)	15 (48)	16 (52)
The training program prompted me to critically evaluate my own communication skills in relation to genetic testing	1 (3)	4 (13)	0 (0)	16 (52)	10 (32)

Percentages may not add up due to rounding. One participant did not provide responses to any of the items

Manchester scoring [37]; (v) complex scenarios (e.g. provide information on how to proceed if patients have family members who have already been tested and have been found to be negative, but the family is still at high risk); and (vi) updates (e.g. offer updates to the program to be emailed to people who have completed the program to allow them to keep their knowledge current).

Discussion

While online training programs have been developed for a range of healthcare professionals in many different healthcare contexts (see [32–34]), we are not aware of any that specifically trained medical specialists in cancer genetics, although Houwink et al. developed and tested a website to train general practitioners in the Netherlands in cancer genetics [7, 40]. Thus, our website fills an important gap in the suite of training resources available for non-genetics healthcare professionals in Australia and is one of the first internationally to specifically focus on mainstreaming of germline testing for cancer genetics.

The current pilot study surveyed predominantly medical oncologists, surgeons and oncology nurses who had completed the program in relation to satisfaction with, and acceptability of, the online program as well as self-rated competence in communicating with breast and ovarian cancer patients about genetic testing following program completion. The majority of participants were satisfied with the information contained in the program, found the program helpful and reported that they had gained new skills from the program relating to communicating with breast and ovarian cancer patients about genetic testing. None reported that the training program was too long, indicating that busy oncology healthcare professionals did not find the time to complete the training onerous. Following completion of the training program, most participants reported that they were confident in communicating with breast and ovarian cancer patients about genetic testing. These findings demonstrate that the online training program was successful in meeting its objectives.

Participants also made a number of suggestions for improvements including providing training about genetic testing in other contexts, for example *BRCA1/2*-positive pancreatic cancer as well as training which targets pathogenic variants in genes other than *BRCA1/2*. These results indicate that a whole suite of training interventions may be needed to meet oncology healthcare professionals' current needs to cover the increased range of germline testing in different cancers where testing is already being offered. Indeed, when this training website was first developed, the intention was to be able to modify it and add more modules to it, as more cancers could be tested under the Medicare Benefits

Scheme in the future, e.g. colorectal cancers. A web portal with a wide range of different modules for users to choose from may be ideally suited to meet healthcare professionals' needs. A core module with generic content might be presented, together with specific modules that address disease-specific issues. This approach has been shown to work well in other contexts [41]. The current website and its evaluation will provide some guidance as to the possible contents of individual modules comprising such web portals. Other suggestions for improvements made by participants included emailing updates to the program to people who have completed the program to allow them to keep their knowledge current. Other options for updating may include regular webinars, where those who have previously completed the training program are invited.

During the COVID-19 pandemic, online teaching has become more common and acceptable due to restrictions on travel and conference attendance [42, 43]. It provides a cost-effective strategy for dissemination of new knowledge and skills training that ensures healthcare professional safety. Another approach has been to use videos in a webinar or have an actor playing the role of the patient in webinars for interactions to be practiced, rather than “live” at a central venue. This program could be adapted to such an approach. As genetic testing results may also be delivered via telehealth, this approach allows participants to learn how to use this medium effectively.

About one quarter of participants did either not believe that the videos in the program were useful or were unsure. The videos featured experts in cancer genetics, rather than professional actors, reflecting the low budget we had available. It is possible that more sophisticated videos, e.g. professionally produced videos featuring actors to play the role of patients and healthcare professionals to engage users in experiential learning activities, might have resulted in higher participant satisfaction. We have recently demonstrated that an online training website with video-based patient vignettes using professional actors can be used successfully to show exemplary clinician behaviours in the context of communication skills training in oncology [38]. Similar videos could be produced for training in cancer genetics, and such videos could be adapted for use in “live” webinars and training with actors. The recent Australian survey of medical specialists regarding their continuing education needs relating to genomic medicine shows that participants believed that experiential learning in genomic medicine was necessary to develop the confidence and skills needed for clinical care [22]. Hence, an important aim of future research should be to develop communication skills training programs specific to cancer genetics incorporating experiential learning activities. Such learning activities could incorporate watching videos and practicing with peers. Studies using similar experiential learning have demonstrated that communication skills

training of oncologists increases the number of observable communication skills utilised by specialists in both simulated and actual consultations following training [44, 45].

The limitations of this study should be mentioned. First, it is unknown how many participants received the invitation to the study, and therefore it is not possible to report the response rate and assess participation bias. Oncology healthcare professionals were asked whether they had gained new skills from the program; however, this question should have been asked differently given they have not yet had an opportunity to use these new skills in practice. A follow-up assessment (e.g. six months after completion of the modules) would have been helpful to assess whether there was a gain in skills. Participants were asked to self-rate competence, and we did not objectively measure competence. Future studies should record consultations involving patients to demonstrate actual increases in the quality of communication and include direct assessments of patient outcomes as well as measurements against published competencies [46]. Another limitation was that the modules were restricted to genetic testing in the *BRCA1/2* genes and did not include testing of other breast and ovarian cancer genes. Given the promising results from this pilot study, future studies should include randomised trials to evaluate whether the program changes clinical practice and improves patient outcomes. Future studies should also assess whether the online program actually leads to an increase in the use of genetic testing. Moreover, future studies should compare the effects of online training to blended models that combine some face-to-face with online learning.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10689-021-00261-1>.

Acknowledgements We are thankful to all participants for giving their time to complete the evaluation. The development of the training website was funded by AstraZeneca, and the pilot study was funded by the Translational Cancer Research Network, Cancer Institute New South Wales. Bettina Meiser was supported by a Senior Research Fellowship Level B (ID 1078523) from the National Health and Medical Research Council (NHMRC) of Australia. Paula Woodward was supported by funding from AstraZeneca to develop the training website. Phyllis Butow was funded by an NHMRC Senior Principal Research Fellowship. Megan Best was funded by a Cancer Institute New South Wales Early Career Fellowship. Frances Boyle is supported by the friends of the Mater Foundation. Katy Bell was supported by an Investigator Grant (ID 1174523) from the National Health and Medical Research Council (NHMRC) of Australia.

Author contributions BM: conceptualization, methodology, formal analysis, investigation, writing original draft, writing—review & editing, funding acquisition. PW: conceptualization, methodology, writing—review & editing, funding acquisition. MG: conceptualization, methodology, writing—review & editing. MK: conceptualization, methodology, writing—review & editing. HMF: conceptualization, methodology, writing—review & editing. YA: conceptualization, methodology, writing—review & editing. PB: conceptualization, methodology, writing—review & editing. FB: conceptualization, methodology,

writing—review & editing. MB: conceptualization, methodology, writing—review & editing. NT: conceptualization, methodology, writing—review & editing. KB: conceptualization, methodology, writing—review & editing. writing—review & editing. KT: conceptualization, methodology, writing—review & editing.

Data availability Data will be made available upon reasonable request.

Declarations

Conflict of interest Margaret Gleeson and Maira Kentwell declare remunerated consultant roles with the company AstraZeneca with respect to activities unrelated to this article. Paula Woodward had a remunerated consultant role with respect to the current study. The other authors declare that they have no conflicts of interest.

Ethical approval This study was approved by the University of New South Wales (UNSW) Human Research Ethics Advisory Panel (Biomedical), approval number 180586.

Consent to participate Informed consent was sought from all research participants.

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Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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