Key messages for communicating information about *BRCA1* and *BRCA2* to women with breast or ovarian cancer: consensus across health professionals and service users

Key messages about *BRCA1/BRCA2*

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ABSTRACT

Objectives: Genetic testing of cancer predisposing genes will increasingly be needed in oncology clinics in order to target cancer treatment. This Delphi study aimed to identify areas of agreement and disagreement between genetics and oncology health professionals and service users about the key messages required by women with breast/ovarian cancer who undergo *BRCA1/BRCA2* genetic testing and the optimal timing of communicating key messages.

Methods: Participants were 16 expert health professionals specialising in oncology/genetics and 16 service users with breast/ovarian cancer and a pathogenic *BRCA1/BRCA2* variant. On-line questionnaires containing 53 inductively developed information messages were circulated to the groups separately. Participants rated each message as key/ not key on a Likert scale and suggested additional messages. Questionnaires were modified according to the feedback and up to three rounds were circulated. Consensus was reached when there was ≥75% agreement.

Results: Thirty key messages were agreed by both groups with seven of the key messages agreed by ≥95% of participants: dominant inheritance, the availability of predictive testing, the importance of pre-test discussion, increased risk of breast and ovarian cancer and the option of risk reducing mastectomy and bilateral salpingo-oophorectomy. Both groups agreed that key messages should be communicated pre- and post genetic testing.

Conclusions: There was a high level of agreement within and between the groups about the information requirements of women with breast/ovarian cancer about *BRCA1/BRCA2*. These key messages will be helpful in developing new approaches to the delivery of information as genetic testing becomes further integrated into mainstream oncology services.

Key words: key messages, *BRCA1/BRCA2*, breast/ ovarian cancer, pre/post genetic test information, oncology/ genetics health professionals, genetic testing

BACKGROUND

There is consensus in the UK that the current system of providing cancer genetic testing through specialist genetics services does not have the capacity to meet the demand raised by advances in genomic medicine [1]. Genetic testing and the delivery of information about cancer predisposing genes for cancer patients will therefore increasingly need to take place in the oncology clinic. The findings from this study, investigating agreement and disagreement amongst oncology and genetics health professionals and service users about the information required by women with breast or ovarian cancer about *BRCA1/BRCA2* testing, will be helpful in informing current and future clinical practice.

Several studies have investigated the information communicated during genetic counselling about *BRCA1/BRCA2* variants [2 3 4]. Women with cancer have more unmet information needs following genetic counselling than women without cancer [5]. Women undergoing genetic testing shortly after diagnosis to facilitate treatment decisions prefer brief cancer risk information without statistics and hope-giving information about options to address the risks [6,7].

There are differences in the approach, focus and training of health professionals specialising in oncology and genetics which are likely to impact on the information communicated. Clinical genetics focuses the family and involves information exchange and the provision of support [8]. Oncology focuses on the individual [9] and initiation of treatment. Oncology health professionals are not always confident in genetic risk assessment [10], may be concerned about causing distress by genetics referral [11], are not always clear about who is responsible for making referrals [12] and do not consistently refer patients even if they have been identified [13-15].

Clinical guidelines recommend pre-test genetic counselling to enhance patients' understanding of the implications of testing for themselves and their families and to enable informed consent [16,17]. Not having pre and post-test counselling has been associated with negative outcomes [18]. Post-test counselling with affected women has been shown to significantly increase the proportion of at risk relatives who make contact with a genetics service [19]. However, non-genetics heath professionals ordering genetic tests in the USA frequently do not schedule a pre-test counselling session [20].

As the issues around genetic testing become increasingly complex, it will be important to develop tailored and streamlined protocols for pre and post-test counselling. This study aimed to investigate areas of agreement and disagreement between expert health professionals and service users about the messages required by affected women about *BRCA1/ BRCA2* and the timing of communicating key messages.

METHODS

Design: The study design was a Delphi consensus exercise [21] with health professionals and service users who had expert professional or personal experience in this field. The Delphi consensus method involves several rounds of survey with a group of experts who anonymously respond and then receive feedback on the group response before being sent a subsequent survey to complete. The goal is to reduce the range of responses with a view to achieving consensus [22].

Developing the questionnaire: An earlier study [23] identified the information communicated during genetic counselling with affected women following identification of a pathogenic *BRCA1/BRCA2* variant. A key message was defined as: 'information required by the individual with cancer in order to understand the risks, implications and options for themselves and their relatives and to decide on a course of action that is appropriate for them'. This definition was derived from the cognitive and behavioural aspects of the definition and published goals of genetic counselling [24] and refined, together with criteria to assist with focusing on the definition, in a pilot study with eight expert genetics health professionals. The questionnaire was developed using the Qualtrix software and tested for comprehension, readability and usability by a genetics health professional, an oncology health professional and a service user (the study interest group).

Participants: Purposive sampling methods were used to identify 16 health professionals with expert knowledge and 16 service users with breast/ovarian cancer and personal experience of diagnostic testing for *BRCA1/BRCA2* variants within the National Health Service (NHS). The sample size was selected in order to recruit an appropriately experienced expert group of health professionals and an equivalent number of service users. Service users were required to be female and to have had breast or ovarian cancer and a pathogenic *BRCA1/BRCA2* variant identified after publication of the NICE guidelines for familial breast cancer [25]. All participants

were required to have an interest in the topic, the capacity, willingness and time to take part, be accessible by email and able to communicate in English.

Health professionals were identified by personal contact, recommendation of senior colleagues or participation at a senior level in relevant UK professional organisations, such as the UK Cancer Genetics Group or BASO – The Association for Cancer Surgery. Approach was made by personal email and study information was provided. Return of the questionnaire was accepted as consent to take part.

Service users were identified via UK voluntary organisations that provide support and information for *BRCA1/BRCA2* carriers. Potential participants who expressed an interest were telephoned to explain the study, determine eligibility and answer any questions. Eligible participants were sent a participant information sheet and consent form.

Sample: Health professionals were four clinical geneticists, four genetic counsellors, two clinical nurse specialists, two gynaecological oncologists, two breast surgeons and two clinical oncologists. All health professionals worked within multidisciplinary teams in teaching hospitals. All genetics health professionals worked in consultant/senior positions within regional genetics centres, counselling/managing affected women about a pathogenic *BRCA1/BRCA2* variant at least once a week. Six of the oncology health professionals worked in consultant/senior positions and two were sub-specialty doctors in the last year of training. Seven of the oncology health professionals managed/cared for/counselled affected women at least once a month and one discussed genetics referral two to three times a week (shown in Supplementary table 1). All 16 participants completed the round 1 questionnaire. One geneticist and one clinical oncologist did not continue beyond round 1. The other 14 health professionals continued with the study.

Of the 16 service users, five were *BRCA1* carriers and 11 were *BRCA2* carriers. The mean age was 53 (range 43 to 69 years): nine had breast cancer, three had ovarian cancer and four had breast and ovarian cancer. Two participants were tested immediately after diagnosis and 14 underwent testing after treatment. Ten participants were educated to degree level or above, six completed education between age 16 and 18 (shown in Supplementary table 2). Sixteen participants completed the round 1 questionnaire, 14 completed round 2 and 12 completed round 3.

Procedure: Ethics approval was granted. Data were collected between November 2013 and October 2014.

The questionnaire included information about the purpose of the study, the definition of a key message and the information messages. The data were analysed separately for each group. The questionnaire was amended at each round according to the data from the previous round. An agreement level of ≥75% was selected [26]. At each round, messages agreed as key or not key were removed from circulation. Remaining messages were re-circulated up to three times or until agreement was reached. Messages that did not reach agreement were circulated together with the median score, range of responses and summarised anonymised comments. The neutral option was removed after the first circulation of each message in order to increase positive or negative responses.

Participants were asked to decide if each message was key or not key using a 5-point Likert scale with options ranging from 'a key message' to 'not a key message'. Messages with a definite response were scored higher than those with a less definite response in order to capture the extent of certainty about the message.

The first time a message was circulated, comments were invited on the wording of the message, the reasons for selection and potential additional key messages. For feasibility, changes to wording and suggested additional messages were accepted when suggested by two or more participants or for consistency with other messages.

For messages assessed as key/ probably key, participants were asked to decide whether the message should be communicated, before testing, once a pathogenic variant has been detected, at both times or at another time altogether. Each response was equally rated as 1.

Analysis: The mean score and its standard deviation (SD) for each message at each round and for each group was calculated using these functions in SPSS. The final mean score and SD for each message was calculated once agreement was reached or, for messages where no agreement was reached, at the end of round 3. Where participants did not continue, their last recorded score was counted as their final score. Mean scores for each group were organised in descending order,

enabling identification of messages with ≥75% agreement as key or not key messages and those where no agreement was reached, messages where no agreement was reached.

The number of messages circulated and agreed as key or not key at each round was documented for each group.

Analysis of the timing of communication involved identifying the number and percentage of responses in each time point for key messages. Agreement was reached when there was ≥75% agreement about the timing of communication of the key message.

RESULTS

Key messages: Health professionals agreed on 34 key messages and 18 messages that were not key. The key messages are shown in Supplementary table 3). There was no agreement about 11 messages.

Service users agreed on 35 key messages and 11 messages that were not key (shown in Supplementary table 4). There was no agreement about 17 messages.

Health professionals *and* service users agreed on 30 key messages. These key messages are shown in abbreviated form in Table 1. (The full wording of all key messages is available in Supplementary tables 3 and 4).

Seven key messages reached ≥ 95% agreement amongst both groups. These key messages are shown in full in Table 2. Both groups agreed that 10 messages were not key. There was disagreement between the groups about three messages. These messages are shown in full in Table 3.

[Insert Table 1]
[Insert Table 2]
[Insert Table 3]

There was agreement by one group only about six messages. Health professionals agreed that messages about the variant not 'skipping a generation', male inheritance and the outcomes of diagnostic testing were key messages; there was no agreement amongst the service users about these messages. Service users agreed that messages about genetic testing and insurance, the risk of male breast cancer and breast awareness were key messages; there was no agreement amongst the health professionals about these messages. These data are shown in Supplementary tables 3 and 4.

Reaching agreement: Fifty-three messages were circulated in round 1 and a further 10 were added in round 2. Health professionals agreed on 21/34 key messages (62%) the first time the message was circulated, 5/34 (14.5%) the second time and 8/34 (23.5%) the third time.

Service users agreed on 23/35 key messages (66%) the first time the message was circulated; 4/35 (11%) the second time and 8/35 (23%) the third time.

Health professionals *and* service users agreed on 14/30 key messages (47%) the first time the message was circulated, 6/30 (20%) the second time and 10/30 (33%) the third time. Neither group reached agreement about eight messages.

Timing of communicating key messages: Health professionals agreed on the timing of communicating 18/34 (53%) key messages. For 17/18 of these, it was agreed that the optimal timing of communication is before testing *and* once a pathogenic variant has been identified. It was agreed that the message about specifying the name of the gene involved should be communicated only once a pathogenic variant has been identified.

Service users agreed on the timing of communicating 25/35 (71%) key messages. For all of these key messages it was agreed that the optimal timing of communication is before genetic testing *and* once a variant has been identified.

Health professionals *and* service users agreed that 13/30 (43%) key messages should be communicated before genetic testing *and* once a variant has been identified.

DISCUSSION

The high level of agreement within the health professionals' group suggests shared professional knowledge between oncology and genetics health professionals despite differences in training, focus and approach. This is reassuring given the need for closer integration between oncology and genetics services. The high level of agreement between service users and health professionals suggests consistency in the information provided during genetic counselling in the UK as lay understandings are inclined to incorporate medical concepts and ideas, even if the form of the knowledge changes slightly [27]. This, together with raised general awareness about hereditary breast and ovarian cancer over recent years [28], may have contributed to the high level of agreement overall.

The messages where there was disagreement between the groups and those agreed as key messages by one group only, suggest differences in the prior knowledge and priorities of the groups. The messages agreed as key messages by only the health professionals group refer to the potential implications of testing and inheritance, some of which are included within the NICE guidelines for familial breast cancer [16]. These messages may not have been obviously relevant to the service users, given that concepts of inheritance are constructed from family experience and relationships [29]. Consistent with research indicating that cancer patients prefer to be fully informed about their illness [30 31], the messages agreed as key by only the service users group refer to information that empowers women to take action to protect themselves and their families, raising awareness and providing hope, even in the absence of clear evidence or surveillance. The health professionals may have been mindful of the relationship between the amount of information given and the proportion recalled [32] and wanted to manage the volume and complexity of the information communicated by focusing on information of relevance to affected women.

Amongst both groups, the majority of key messages were agreed the first time they were circulated. The findings of this study are validated by the ease of reaching agreement within and between the groups and the high response and retention rate.

For the key messages where timing of communication was agreed, 'before genetic testing *and* once a variant has been detected' was the most popular choice. These findings highlight the value placed by service users with cancer on pre and post-test communication of genetic information.

Study limitations: This study did not address the specific information needs of unaffected women undergoing genetic testing, affected women undergoing treatment-focused or multi-gene panel testing, affected men, the post-test information needs of affected women who do not have a *BRCA1/BRCA2* variant or how and by whom the information is best communicated. Other studies have demonstrated effective delivery of pre-test information about genetic testing for *BRCA1/BRCA2* using written[33], digital, telephone-based [34] and DVD-based communication [34,35]. As the messages were developed inductively from post-test genetic counselling consultations, some messages recommended by clinical guidelines [16] , such as the meaning of a 'no mutation detected' result, the timescale of results and confidentiality, were not included in the questionnaires. Participants were invited to suggest additional messages in order to overcome this potential issue. However, two or more participants did not suggest that these were key messages. Similarly, some messages, such as the importance of multidisciplinary team involvement and the availability of psychological support, did not reach agreement as key or not key by either group. Finally, the small sample size and heterogeneity of the groups may limit generalizability of these findings.

Clinical implications: The key messages identified in this study are not intended as a didactic list; some messages will not be relevant to all women and some women will want more or less information. However, the key messages do provide a guide for communicating with affected women about *BRCA1/BRCA2* genes and are a reminder that some information considered key by health professionals may not be considered key by women with cancer and vice versa.

Health professionals need to remain up to date with changes that may affect the key messages and carefully explain the nuances of the messages. This is highlighted by the recent challenge to the evidence regarding breast cancer risk reduction associated with risk reducing bilateral salpingo-oophorectomy [36-38].

Where time or the ability to assimilate information is limited, for example for women undergoing testing to determine cancer treatment, the messages with the highest level of agreement provide a minimum set of key messages to communicate: dominant inheritance, the availability of predictive testing, the importance of pre-test discussion, increased risk of breast and ovarian cancer and the option of risk reducing mastectomy and bilateral salpingo-oophorectomy.

Drawing on current practice and expert opinion, this study has provided evidence of the key messages required by affected women about *BRCA1/BRCA2* and the optimal timing of communication. The findings will be helpful in developing new approaches to the delivery of information as genetic testing becomes further integrated into mainstream oncology services.

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DISCLAIMER

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Table 1. Key messages agreed by ≥75% of health professionals *and* service users

(BC breast cancer, OC ovarian cancer, FTC fallopian tube cancer, PPC primary peritoneal cancer, PC prostate cancer, RRM risk reducing mastectomy, CM contralateral mastectomy, RRBSO risk reducing salpingo-oophorectomy)

BRCA1/BRCA2 gene faults are dominantly inherited.
Identifying the side of the family at risk is important.
A *BRCA1/BRCA2* gene fault may explain the family history.
The fault is in the *BRCA1/BRCA2* gene (specify).
Cancer is not inevitable for carriers.
Predictive testing is available for relatives once a fault has been detected.
Women at 50% risk of a *BRCA1/BRCA2* gene fault are eligible for high-risk breast screening.
Inform all at risk relatives that genetic testing is available.
Discussing the implications and possible outcomes prior to testing is important.
The decision to be tested is up to each individual.
Female *BRCA1/BRCA2* carriers with BC are at increased risk of further primary BC.
Female *BRCA1/BRCA2* carriers with OC/FTC are at increased risk of BC.
Female *BRCA1/BRCA2* carriers with breast cancer are at increased risk of OC/FTC.
Female *BRCA1/BRCA2* carriers without cancer are at increased risk of breast cancer.
For female *BRCA1/BRCA2* carriers the risk of BC between age 25 and 30 may be increased. Most of the risk occurs after age 30.
Female *BRCA1/BRCA2* carriers without cancer are at increased risk of OC, FTC and PPC.
For female *BRCA1* carriers the risk of OC before age 40 may be increased. Most of the risk occurs after age 40. For female *BRCA2* carriers most of the risk occurs after age 45.
Male *BRCA1/ BRCA2* carriers are at increased risk of PC. The risk is higher in *BRCA2* than *BRCA1*.
RRM is an option for female *BRCA1/BRCA2* carriers.
Breast reconstruction is an option after mastectomy.
RRM reduces the risk of BC (but a small risk remains).
Annual breast screening is available from age 30 for female *BRCA1/BRCA2* carriers.
There are limitations to breast screening.
Ovarian screening is not effective or available. Women with symptoms should see their GP.

Once the risk of ovarian cancer starts to rise, RRBSO is an option for female *BRCA1/BRCA2* carriers.
RRBSO reduces the OC/FTC risk (but a small risk of PPC remains).
RRBSO before the natural menopause may reduce the risk of primary BC by up to 50% in unaffected *BRCA2* carriers. *
BSO will result in menopause.
Genetic testing may provide helpful risk and management information for female *BRCA1/BRCA2* carriers with cancer.
RRM or CM will reduce the risk of a new primary BC but will not reduce the risk of metastases from the initial cancer.
* *Wording amended to reflect challenges to earlier evidence* [36-38]

Table 2. Key messages agreed by ≥95% of health professionals *and* service users

The children of a person with a *BRCA1/BRCA2* gene fault each have a 50% (1 in 2) risk of inheriting the gene fault.
Predictive (targeted) genetic testing is available for relatives once a *BRCA1/BRCA2* gene fault has been identified. This will show whether or not the person has inherited the known faulty gene, and so predicts whether they might be at risk (this is called a predictive test).
Before having a genetic test it is important to discuss the implications and possible outcomes.
Breast cancer risk is increased for women without cancer who have a *BRCA1/BRCA2* gene fault.
For women who have a *BRCA1/BRCA2* gene fault, ovarian cancer (including fallopian tube and primary peritoneal cancer) risk is increased.
Risk Reducing Mastectomy (surgery to remove the breasts in order to reduce the risk of cancer) is an option for women who have a *BRCA1/BRCA2* gene fault.
Once the risk of ovarian cancer starts to rise, Risk Reducing Bilateral Salpingo-Oophorectomy (surgery to remove the ovaries and fallopian tubes in order to reduce the risk of cancer) is an option for women who have a *BRCA1/BRCA2* gene fault.

Table 3. Areas of disagreement between health professionals *and* service users

	Health professionals		
		Key message	**Not key**
Service users	**Key**		A *BRCA2* gene fault may slightly increase the risk of other cancers, such as pancreatic, gall bladder and bile duct cancer. However, the risks are small and there is no screening available.
			Diet and lifestyle can make a difference to the risk of cancer generally but the impact is likely to be small compared with the risk associated with the *BRCA1/BRCA2* gene fault.
	Not key	If a person does not inherit a known *BRCA1* or *BRCA2* gene fault, their risks of breast/ ovarian/ prostate cancer will be similar to other people in the general population.	

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