



BIROn - Birkbeck Institutional Research Online

Jacobs, C. and Dancyger, Caroline and Smith, Jonathan A. and Michie, S. (2015) Accuracy of recall of information about a cancer-predisposing BRCA1/2 gene mutation among patients and relatives. *European Journal of Human Genetics* 23 , pp. 147-151. ISSN 1018-4813.

Downloaded from: <https://eprints.bbk.ac.uk/id/eprint/9798/>

Usage Guidelines:

Please refer to usage guidelines at <https://eprints.bbk.ac.uk/policies.html> or alternatively contact lib-eprints@bbk.ac.uk.

1 **Accuracy of recall of information about a cancer predisposing**
2 ***BRCA1/2* gene mutation amongst patients and relatives**

3

4 **Running title: Accuracy of information about a *BRCA1/2* mutation**

5

6 **Authors:**

7 Chris Jacobs, MSc, BSc Guy's and St Thomas' NHS Foundation Trust

8 Caroline Dancyger, D.Clin.Psych Bart's Health NHS Trust, London

9 Jonathan. A. Smith, DPhil, MSc Birkbeck, University of London

10 Susan Michie, DPhil, MPhil University College London

11

12 **Corresponding author**

13 **Name:** Chris Jacobs

14 **Telephone:** 02071881364 (work) 07764948568 (mobile)

15 **Fax:** 020 7188 1369

16 **Email:** Chris.Jacobs@gstt.nhs.uk

17 **Address:** Department of Clinical Genetics,

18 7th Floor, Borough Wing, Guy's and St Thomas' NHS Foundation

19 Trust, Great Maze Pond, London SE1 9RT

20

21

22

23

24

25

1 **ABSTRACT**

2 This observational study aimed to i) compare accuracy of information recalled by
3 patients and relatives following genetic counselling about a newly identified *BRCA1/2*
4 mutation; ii) identify differences in accuracy about genetics and hereditary cancer and
5 iii) investigate whether accuracy amongst relatives improved when information was
6 provided directly by genetics health professionals. Semi-structured interviews
7 following results consultations with 10 breast/ ovarian cancer patients and 22 relatives
8 were audio-recorded and transcribed. Information provided by the genetics health
9 professional was tracked through the families and coded for accuracy. Accuracy was
10 analysed using the Wilcoxon Signed Ranks test. Sources of information were tested
11 using a Spearman's rank order correlation coefficient. 53% of the information
12 recalled by patients was accurate. Accuracy of recall amongst relatives was
13 significantly lower than amongst patients ($p=0.017$). Both groups recalled a lower
14 proportion of information about hereditary cancer than genetics ($p=0.005$). Relatives
15 who learnt the information from the patient alone recalled significantly less accurate
16 information than those informed directly by genetics health professionals ($p=0.001$).
17 Following genetic counselling about a *BRCA1/2* mutation, accuracy of recall was low
18 amongst patients and relatives, particularly about hereditary cancer. Multiple sources
19 of information, including direct contact with genetics health professionals, may
20 improve accuracy of information amongst relatives.

21

22 **Key words:** accuracy, information, *BRCA1/2* mutation, communication, genetic
23 counselling

24

25

1 INTRODUCTION

2 One of the goals of genetic counselling in the context of familial cancer risk is to
3 provide relevant information in order to enable informed decision-making about
4 genetic testing and risk management ¹. Until recently, genetic testing has generally
5 been offered to women with breast or ovarian cancer after completing cancer
6 treatment. However, *BRCA1/2* testing is increasingly offered to women with newly
7 diagnosed breast cancer as part of their oncology management ². Thus the information
8 that the patient understands and recalls about a cancer predisposing gene mutation
9 may impact on treatment decisions as well on as the management of future cancer
10 risks for herself and her relatives ^{3,4}.

11

12 Responsibility for sharing information within families once a cancer predisposing
13 gene mutation has been identified generally falls to the individual with cancer who
14 receives the initial mutation result ⁵. Families prefer information to be passed on by
15 the patient ⁶ yet, although most families do appear to communicate genetic
16 information ⁵, patients do not always share all information with all at risk relatives ^{7,8}.
17 There are many barriers to family communication about hereditary cancer ⁹ including
18 lack of close relationship ⁶, reluctance to upset relatives ¹⁰, youth or emotional
19 readiness of relatives ¹¹, family culture ⁸, perception of the risks and benefits of the
20 information ¹² and personal beliefs about the causes of genetic illness ¹³.

21

22 Information about a cancer predisposing gene mutation does not necessarily lead to
23 changes in risk perception ¹, although the way in which information is communicated
24 within families may influence uptake of genetic counselling and screening ¹⁴.

25 However at risk individuals who are unaware of the implications of a mutation or the

1 available screening protocols may be unable to make informed decisions about
2 whether or not to access genetic testing or screening. For example, in the UK
3 untested women at 50% risk of a known *BRCA1/2* gene mutation are eligible for
4 equivalent screening to women with a mutation¹⁵. Much is still unknown about the
5 content of information that is shared within families or whether the accuracy of the
6 information communicated and recalled impacts on decisions to seek genetic testing
7 or risk management options.

8

9 Few studies have investigated the accuracy of the information recalled by cancer
10 patients or their relatives following identification of a *BRCA1/2* gene mutation.

11 A Belgian study of 107 first-degree relatives of 14 patients with a *BRCA1/2* mutation
12 reported low levels of knowledge amongst patients and relatives about hereditary
13 breast and ovarian cancer, dominant inheritance, the availability of predictive testing,
14 cancer risks, risk reducing options and the possibility of prenatal diagnosis¹⁶. Levels
15 of knowledge about hereditary cancer were found to be higher amongst patients than
16 relatives. More recently a Dutch study found that patients' recall of information
17 about *BRCA1/2* genetic test results was similar to the information provided during
18 genetic counselling but there were few similarities between the information actually
19 communicated to the patient and the information recalled by their relatives¹⁷. The
20 authors concluded that the information was re-interpreted at each stage of the
21 information transfer, highlighting problems with the accuracy of information
22 communicated to relatives by patients.

23

24 Encouraging and facilitating family communication is a key element of genetic
25 counselling^{5,9}. However, an international review found that none of the guidelines

1 about family communication in genetics detailed how or what information should be
2 communicated¹⁸. A worldwide survey of genetic counselling practice in facilitating
3 family communication found that, although 90% of participants stated that they
4 always identify at risk relatives and encourage family communication, 41% never
5 write a letter specifically for at risk relatives¹⁹.

6
7 This observational study aimed to (i) compare the accuracy of information amongst
8 patients and relatives following genetic counselling with index patients about a
9 *BRCA1/2* mutation; (ii) compare the accuracy of information about general genetics
10 and hereditary cancer and (iii) examine whether accuracy amongst relatives improved
11 when information was provided directly by genetics health professionals. This was
12 part of a larger study examining the experience and process of family communication
13 using qualitative and quantitative methods. The qualitative analysis has been reported
14 elsewhere^{8,11,20}.

15

16 **MATERIALS AND METHODS**

17 **Participants:** Eligible participants were women affected by breast or ovarian cancer
18 who had been found to have a pathogenic *BRCA1/2* mutation following diagnostic
19 genetic testing at one of two UK NHS Regional Genetics Centres (patients), and their
20 ‘at risk’ biological relatives with whom they had shared the result (relatives). The
21 study sample consisted of 10 patients with breast and/ or ovarian cancer and 22 of
22 their relatives (at least two ‘at risk’ first, second or third-degree relatives of each
23 patient).

24

1 **Recruitment:** All patients receiving diagnostic *BRCA1/2* genetic test results
2 underwent pre-test genetic counselling and results were given during a subsequent
3 consultation by a genetics health professional (genetic counsellor or clinical
4 geneticist). Patients were recruited after blood was taken for genetic testing but prior
5 to receiving their test result. The patients recruited their relatives after they had
6 shared the result with them. These relatives may or may not have undergone
7 predictive testing at the time of interview. All participants were over the age of 18 and
8 spoke English. Only families where the patient and at least two relatives were
9 interviewed were included.

10

11 Data were collected between 2006 and 2008. Health professionals consented to audio-
12 recording of the consultations and analysis of clinic letters. Participants consented to
13 audio-recording of consultations (for patients only) and research interviews. Ethics
14 approval was obtained.

15

16 **Procedure:** Two researchers, who were employed consecutively on the project,
17 carried out all of the semi-structured interviews. The patients were interviewed on one
18 occasion approximately four weeks after receiving the genetic test result. The
19 interview schedule addressed understanding of genetic risk and implications for
20 themselves and family, whether or not they had informed relatives of the result, how
21 and what information they had given to relatives and how this was received. Specific
22 knowledge questions were not asked. One semi-structured interview was
23 subsequently carried out with each relative, again using an interview schedule.
24 Relatives were asked for details of what and how they were told about the mutation
25 by the patient (i.e. what words were used, how they reacted to the information, how

1 they perceived their own risk, whether they intended to do anything as a result of the
2 information and the sources of their information). Again specific knowledge questions
3 were not asked.

4

5 The transcripts of the clinic consultations and the post-consultation summary letters
6 were systematically searched for information that had been communicated by the
7 health professional. This was grouped into 'general genetics information' (i.e.
8 inheritance, the gene involved and genetic counselling/testing for relatives) and
9 'hereditary cancer information' (i.e. cancer risk for affected and unaffected
10 individuals and risk management options). Interview transcripts were systematically
11 searched for reference to the information that had been communicated by the genetics
12 health professional. The research team agreed on the coding framework and
13 definitions of accuracy. The transcripts of the patients and relatives were coded
14 independently by two researchers for accuracy compared to the information provided
15 by the health professional. Participants' statements that were correct compared to the
16 information provided by the health professional were coded as accurate. Statements
17 that were incorrect, unknown, not mentioned or incomplete were coded as inaccurate.
18 Where a participant made more than one reference to information, these were grouped
19 together and coded once. For example, if the participant had made two references to
20 the same information, one accurate and one inaccurate, this was coded as inaccurate.
21 Relatives' transcripts were also coded for the reported sources of information as
22 follows: information provided by the patient only (coded as information level 1);
23 information provided by the patient and the genetics consultation or a letter from the
24 health professional (coded as information level 2): and information provided by the

1 patient and the genetics consultation and a letter from the health professional (coded
2 as information level 3).

3

4 **Analysis:** Accurate and inaccurate statements were counted using Content Analysis ²¹
5 and analysed using SPSS. Because there were different numbers of relatives in each
6 family (either two or three) the mean number of inaccuracies for the relatives in each
7 family were calculated. Accuracy of recall of information for patients was
8 operationalised as the number of accurate statements made during the interview
9 divided by the total number of accurate and inaccurate statements so that if there were
10 five accurate statements and five inaccurate statements, the accuracy score was 0.5
11 (5/10). Accuracy of recall of information for relatives involved calculating the
12 accuracy score for each relative interviewed, and then calculating the mean score for
13 the relatives as a whole. Thus if there were two relatives in the family and one had an
14 accuracy score of 0.5 and the other had a score of 0.3, the score for the relatives
15 would be 0.4. Accuracy of recall scores were calculated separately for genetics
16 information and hereditary cancer information and for the two combined.

17 *A priori* hypotheses concerning differences in accuracy between patients and relatives
18 and between genetics and hereditary cancer information were tested using the
19 Wilcoxon Signed Ranks test. This evaluated differences between matched pairs of
20 numbers with no assumption about the underlying distribution of those numbers. The
21 alpha was set to 0.05, 2-tailed. Although the hypotheses were directional, it is rare to
22 see the use of a 1-tailed test in this area and the sample size was small. Given this, a
23 conservative approach was adopted and convention of a significance level set at
24 $p < 0.05$ was followed.

25

1 **Sources of relatives' information:** The *a priori* hypothesis, that accuracy of recall of
2 information by relatives is positively associated with the number of sources of
3 information, was tested using a Spearman's rank order correlation coefficient. The
4 alpha was set to 0.05, 2-tailed.

5

6 **RESULTS**

7 **Participants:** Of the patients, six had a *BRCA1* mutation and four had a *BRCA2*
8 mutation; five had breast cancer only, two had ovarian cancer only and three had
9 breast and ovarian cancer. The mean age of the patients was 55.5 years (range 34 to
10 71). The mean age at diagnosis was 40.8 years for breast cancer (range 28 to 59) and
11 56.2 years for ovarian cancer (range 45 to 63). Amongst the relatives, 18 were
12 unaffected with cancer, two had breast cancer (age 45 and 51 years), one had ovarian
13 cancer (age 55) and one had oral cancer (age 63); there were six daughters, four sons,
14 six sisters, two brothers, two nieces and two cousins; 12 were untested, three tested
15 positive, four tested negative and three were awaiting results. The mean age of the
16 relatives was 37.1 years (range 20 to 65) (These data are shown in the supplementary
17 Table).

18

19 **Volume of information communicated to patients:** Overall, 209 information
20 statements were communicated to the patients: 29% (61) relating to general genetics
21 and 71% (148) relating to hereditary cancer. The mean number of information
22 statements communicated to patients was 21 (range 16 to 26).

23

24 **Accuracy of recall:** The percentage agreement for independent coding of accuracy of
25 participants' statements by two members of the research team (CJ and CD) was 94%

1 (627/667). All disagreements were readily resolved. **Table 1** shows accuracy and
2 inaccuracy across all families for all information (the relatives' score shown is the
3 mean score for the relatives in each family).

4 **[Insert Table 1]**

5 Accuracy of recall of information overall (in relation to genetics and hereditary cancer
6 combined) was low amongst the patients following genetic counselling (53%).

7 Accuracy amongst the relatives was significantly lower (30%) than amongst the
8 patients themselves (Wilcoxon Signed Ranks test $z=2.40$, $p=0.017$, 2-tailed). Overall
9 accuracy of patients and relatives is shown in **Table 2**.

10 **[Insert Table 2]**

11 The accuracy of recall for patients and relatives combined was greater for general
12 genetics information (60%) than for hereditary cancer information (36%) ($z=2.80$,
13 $p=0.005$). There was a trend suggesting that this difference was greater for patients
14 than for relatives (Wilcoxon Signed Ranks test, $z=1.89$, $p=0.056$). **Table 3** shows
15 accuracy and inaccuracy about general genetics and hereditary cancer information for
16 patients and relatives.

17 **[Insert Table 3]**

18 **Sources of information:** There was a positive association between the accuracy of
19 recall by relatives and the number of sources of information (Spearman's rank order
20 correlation coefficient $R=0.88$, $p=0.001$) (**Table 4**). This was the case both for
21 hereditary cancer ($R=0.83$, $p=0.003$) and general genetics information ($R=0.72$,
22 $p=0.02$).

23 **[Insert Table 4]**

24 **DISCUSSION**

1 Only 53% of the information about general genetics and hereditary cancer recalled by
2 patients was accurate. The reasons for the low levels of accuracy amongst patients
3 were not investigated in this study. However, it is possible that the high volume of
4 information communicated by health professionals (mean of 21 statements of
5 information) may have contributed to the low recall amongst patients, as suggested by
6 previous authors ^{22,23}.

7

8 Accuracy of recall amongst relatives was significantly lower than accuracy amongst
9 patients. The reduction in accuracy of recall as information was communicated to
10 relatives is consistent with the findings of previous studies ^{16,24}. Patients and relatives
11 differed in their experiences of cancer and their age at interview (patients' means age
12 was 55.5 and relatives' means age was 37.1). These differences may have contributed
13 to the lower level of accuracy amongst relatives. As previous research has suggested,
14 there are a number of possible reasons why information may not be recalled following
15 genetic counselling about a *BRCA1/2* mutation including lack of understanding ²⁴,
16 individual interpretation or perceived lack of relevance ⁸ and not valuing the
17 information sufficiently to retain it ¹¹.

18

19 A lower level of accuracy was seen about hereditary cancer than genetics amongst
20 patients and relatives. This supports the findings of a previous study of accuracy of
21 recall of patients with cancer and their relatives which found that information about
22 cancer risk was the least accurately recalled ²⁵. However, in a study of first-degree
23 relatives undergoing predictive testing for *BRCA1/2* mutations, higher levels of
24 accuracy about hereditary cancer than inheritance were reported ¹⁶. For the cancer
25 patients in this study, general genetics information would have been addressed during

1 pre-test genetic counselling, whereas specific hereditary cancer information may not
2 have been discussed in detail prior to learning the genetic test result. The patients
3 may therefore have been less familiar with some or all of the hereditary cancer
4 information than with the general genetics information. This may have contributed to
5 the lower levels of accuracy about hereditary cancer amongst patients and relatives.

6
7 Giving information about the implications of genetic testing in order to enable
8 informed decision-making is an integral component of genetic counselling^{26,27}. Yet it
9 is not known whether the accuracy of information recalled about an identified gene
10 mutation impacts on the decisions that individuals make regarding genetic testing or
11 risk management. A systematic review of the effect of communicating DNA based
12 risk assessments on risk reducing behaviour found that there was insufficient evidence
13 to draw conclusions for practice²⁸. Ley's model of effective communication in
14 medical practice stresses the importance of accurate recall, satisfaction and adherence
15 for understanding²⁹. However, Fuzzy Trace Theory suggests that individuals encode
16 multiple representations of information with varying precision, enabling
17 understanding of the 'gist' rather than the detail of information³⁰. It is possible that
18 understanding the gist of the information is sufficient for individuals to make
19 decisions in this context. It is unclear whether there is a link between accurately
20 recalling the information and the uptake of genetic testing and screening or the
21 information individuals require about a *BRCA1/2* mutation in order to make these
22 decisions.

23

24 Relatives who received information from several sources, including the genetics
25 health professional, reported a higher level of accurate information recall than those

1 who received information from the patient alone. This suggests that multiple sources
2 of information may improve the accuracy of information recalled by relatives.
3 However, why this was the case or how accuracy was improved was not investigated
4 by the study. Previous research has suggested that information provided to relatives
5 by genetics health professionals may involve less interpretation and emotion than that
6 provided by index patients²⁴. This would also be in line with Family Systems Theory
7³¹ in which illness, or in this case the genetic test result, influences and is influenced
8 by the individuals within the family who interpret and manage interactions relating to
9 the illness.

10

11 The patients in this study were tested after completing cancer treatment and were
12 counselled by genetics health professionals with greater knowledge and expertise in
13 genetics than cancer. The integration of genetics into mainstream medicine will
14 inevitably shift the timing, location and focus of the delivery of information about
15 genetic testing. These discussions are increasingly likely to take place prior to, or
16 during, treatment and to be delivered by health professionals with greater knowledge
17 and expertise in cancer than genetics. Although these findings are not directly
18 transferable to that scenario, they may provide a basis for further research.

19

20 This study was limited to a self-selected sample and the participants were not assessed
21 on recall of specific information. Accuracy of the information recalled compared with
22 the information communicated by the health professional was drawn from qualitative
23 data and involved judgements made by the research team but the use of an agreed
24 definition of accuracy, the coding framework and high level of agreement by two
25 researchers coding independently strengthened the study. Given changes in public

1 awareness of genetics and in the availability of verbal and written provision of
2 information, there may have been changes in the understanding by relatives since the
3 time of data collection in this study from 2006 to 2008. It follows that the findings
4 may be different if the study were to be repeated now with a new sample. In order to
5 assess the generalizability of the findings, they would need to be replicated on a larger
6 scale and evaluated in other settings, with other populations and with patients
7 undergoing genetic testing close to diagnosis.

8

9 Further study is needed to examine the reasons for the low level of accuracy, the
10 relevance of the information not accurately recalled, the impact of the inaccurate
11 recall and factors that could influence recall, such as educational level, meaning,
12 context, experience and emotion. Further research would be helpful to identify the
13 information that individuals require in order to make risk management decisions and
14 the extent to which accurate recall of information about a *BRCA1/2* mutation is
15 necessary for such decision-making.

16

17 **CONCLUSION**

18 These findings suggest that following identification of a *BRCA1/2* mutation in the
19 clinical genetics setting, accuracy of recall of information amongst patients and
20 relatives is low; particularly about cancer risks and risk management options. The
21 findings highlight the importance of communicating clear and accurate information
22 about general genetics and hereditary cancer to patients and relatives once a gene
23 mutation is identified and suggest that accuracy of recall amongst relatives may be
24 improved when the information is communicated via multiple sources of information,
25 including direct contact with genetics health professionals. These findings provide

1 evidence supporting the concern that at-risk relatives may understand little about their
2 cancer risks and risk management options which could be important for clinical
3 practice.

4

5 **ACKNOWLEDGEMENTS**

6 This study was funded by a National Institute for Health Research (NIHR) Doctoral
7 Research Fellowship award (the larger qualitative study was funded by a Department
8 of Health grant - HSR06). We would like to thank Professor Robert West for his
9 assistance with the statistical analysis, Marietta Papaconstantinou for her contribution
10 to the project, the genetics health professionals for help with recruitment and the
11 patients and relatives who participated.

12

13 **DISCLAIMER**

14 This article presents independent research funded by the National Institute for Health
15 Research (NIHR). The views expressed are those of the authors and not necessarily
16 those of the NHS, the NIHR or the Department of Health.

17

18 **CONFLICT OF INTERESTS**

19 The authors declare no conflict of interest.

20

21 **REFERENCES**

22 1. Braithwaite D, Emery J, Walter F, Prevost AT, Sutton S: Psychological
23 impact of genetic counseling for familial cancer: a systematic review and
24 meta-analysis. *Fam Cancer* 2006; **5**: 61-75.

25

- 1 2. Pal T: Genetic risk assessments in individuals at high risk for inherited
2 breast cancer in the breast oncology care setting. *Cancer Control* 2012;
3 **19**: 255.
4
- 5 3. Timmermans DR, Ockhuysen-Vermeij CF, Henneman L: Presenting health
6 risk information in different formats: the effect on participants' cognitive
7 and emotional evaluation and decisions. *Patient Educ Couns* 2008; **73**:
8 443-447.
9
- 10 4. Croyle RT, Lerman C: Risk communication in genetic testing for cancer
11 susceptibility. *J Natl Cancer Inst Monogr* 1999: 59-66.
12
- 13 5. Hayat Roshanai A, Lampic C, Rosenquist R, Nordin K: Disclosing cancer
14 genetic information within families: perspectives of counselees and their
15 at-risk relatives. *Fam Cancer* 2010; **9**: 669-679.
16
- 17 6. Forrest K, Simpson SA, Wilson BJ *et al*: To tell or not to tell: barriers and
18 facilitators in family communication about genetic risk. *Clin Genet* 2003;
19 **64**: 317-326.
20
- 21 7. Gaff CL, Clarke AJ, Atkinson P *et al*: Process and outcome in
22 communication of genetic information within families: a systematic
23 review. *Eur J Hum Genet* 2007; **15**: 999-1011.
24

- 1 8. Dancyger C, Wiseman M, Jacobs C, Smith JA, Wallace M, Michie S:
2 Communicating BRCA1/2 genetic test results within the family: A
3 qualitative analysis. *Psychology & Health* 2011; **26**: 1018-1035.
4
- 5 9. Chivers Seymour K, Addington-Hall J, Lucassen AM, Foster CL: What
6 facilitates or impedes family communication following genetic testing for
7 cancer risk? A systematic review and meta-synthesis of primary
8 qualitative research. *J Genet Couns* 2010; **19**: 330-342.
9
- 10 10. Hughes C, Lerman C, Schwartz M *et al*: All in the family: evaluation of the
11 process and content of sisters' communication about BRCA1 and BRCA2
12 genetic test results. *Am J Med Genet* 2002; **107**: 143-150.
13
- 14 11. Dancyger C, Smith JA, Jacobs C, Wallace M, Michie S: Comparing family
15 members' motivations and attitudes towards genetic testing for
16 hereditary breast and ovarian cancer: a qualitative analysis. *European*
17 *Journal of Human Genetics* 2010; **18**: 1289-1295.
18
- 19 12. Gallo AM, Gallo AM, Angst DB, Knafel KA: Disclosure of genetic information
20 within families. *Am* 2009; **109**: 65 -69.
21
- 22 13. Michie S, Smith JA, Senior V, Marteau TM: Understanding why negative
23 genetic test results sometimes fail to reassure. *Am J Med Genet A* 2003;
24 **119A**: 340-347.
25

- 1 14. Peterson SK, Watts BG, Koehly LM *et al*: How families communicate about
2 HNPCC genetic testing: findings from a qualitative study. *Am J Med Genet C*
3 *Semin Med Genet* 2003; **119c**: 78-86.
4
- 5 15. National Institute for Health and Care Excellence: Familial Breast Cancer:
6 Classification and care of people at risk of familial breast cancer and
7 management of breast cancer and related risks in people with a family
8 history of breast cancer CG164. London: 2013.
9
- 10 16. Sermijn E, Goelen G, Teugels E *et al*: The impact of proband mediated
11 information dissemination in families with a BRCA1/2 gene mutation. *J*
12 *Med Genet* 2004; **41**: e23.
13
- 14 17. Vos J, Jansen AM, Menko F, van Asperen CJ, Stiggelbout AM, Tibben A:
15 Family communication matters: the impact of telling relatives about
16 unclassified variants and uninformative DNA-test results. *Genetics in*
17 *Medicine* 2011; **13**: 333-341.
18
- 19 18. Forrest LE, Delatycki MB, Skene L, Aitken M: Communicating genetic
20 information in families--a review of guidelines and position papers.
21 *European Journal of Human Genetics* 2007; **15**: 612-618.
22
- 23 19. Forrest LE, Delatycki MB, Curnow L, Skene L, Aitken M: Genetic health
24 professionals and the communication of genetic information in families:

- 1 Practice during and after a genetic consultation. *Am J Med Genet A* 2010;
2 **152A**: 1458-1466.
- 3
- 4 20. Smith JA, Dancyger C, Wallace M, Jacobs C, Michie S: The development of a
5 methodology for examining the process of family communication of
6 genetic test results. *J Genet Couns* 2011: 1-12.
- 7
- 8 21. Silverman D: *Interpreting Qualitative Data: Methods for Analyzing Talk*
9 *Text and Interaction*, Third edition edn. California Sage, 2006.
- 10
- 11 22. Cowan N: *Working Memory Capacity*. Hove: Psychology Press, 2005.
- 12
- 13 23. Howard D: *Cognitive Psychology*. New York, NY: Macmillan, 1983.
- 14
- 15 24. Vos J, Menko F, Jansen AM, van Asperen CJ, Stiggelbout AM, Tibben A: A
16 whisper-game perspective on the family communication of DNA-test
17 results: a retrospective study on the communication process of BRCA1/2-
18 test results between proband and relatives. *Familial Cancer* 2011; **10**: 87-
19 96.
- 20
- 21 25. Roshanai AH, Rosenquist R, Lampic C, Nordin K: Does enhanced
22 information at cancer genetic counseling improve counselees' knowledge,
23 risk perception, satisfaction and negotiation of information to at-risk
24 relatives?--a randomized study. *Acta Oncol* 2009; **48**: 999-1009.
- 25

- 1 26. Shiloh S, Avdor O, Goodman RM: Satisfaction with genetic counseling:
2 dimensions and measurement. *Am J Med Genet* 1990; **37**: 522-529.
3
- 4 27. Resta R, Biesecker B, Bennett R *et al*: A New Definition of Genetic
5 Counseling: National Society of Genetic Counselors' Task Force Report. *J*
6 *Genet Couns* 2006; **15**: 77-83.
7
- 8 28. Marteau Theresa M, French David P, Griffin Simon J *et al*: Effects of
9 communicating DNA-based disease risk estimates on risk-reducing
10 behaviours: *Cochrane Database of Systematic Reviews*: John Wiley & Sons,
11 Ltd, 2010.
12
- 13 29. Ley P: Memory for medical information. *Br J Soc Clin Psychol* 1979; **18**:
14 245-255.
15
- 16 30. Reyna VF: A theory of medical decision making and health: fuzzy trace
17 theory. *Med Decis Making* 2008; **28**: 850-865.
18
- 19 31. White JK, DM: *Family Theories*. Thousand Oaks, CA: Sage, 2002.
20
21
22