

# Argumentation in Good News Communication on Genetic Breast Cancer. The Experience of OPERA.

Sara Rubinelli and Peter J. Schulz and Paolo Paolini<sup>1</sup>

**Abstract.** This paper addresses the unexplored issue of how to communicate good news to the low-risk population, as a way to reduce anxiety and limit unnecessary demand for consultation. More specifically, we illustrate the design of the low-risk assessment message delivered by OPERA, an online application that we have built for risk assessment of genetic breast cancer. OPERA's central component is an argumentative strategy that applies the UK National Institute of Health and Clinical Excellence' guidelines on the basis of salient attributes of the family and personal history of breast and/or ovarian cancer. More specifically, the strategy uses an essentially deductive argument structure instantiating an appeal to expert opinion, sided by a dialectical component that has the rhetorical aim of taking into consideration and addressing users' potential concerns.

## 1 INTRODUCTION

On 22<sup>nd</sup> April, Cancerbackup, the UK leading provider of information for cancer patients, has launched OPERA (Online Patient Education and Risk Assessment), an online interactive software program that offers personalised information about the risk of having an inherited genetic link in one's own family. OPERA is currently available at: <http://195.176.180.15/opera/>.

Since 2003 Cancerbackup has produced accurate up to date cancer genetic information in hard copy and on Cancerbackup's website. As advances in this complex topic are made at a fast pace, the demand for this type of information continues to grow. As an increasing number of people have access to the internet and turn to it for virtually anything, it seemed that the natural next step for Cancerbackup's genetic information project would be to produce online personalised information on cancer genetic risk, in the form of an interactive risk assessment tool.

The risk level and the appropriate management options run by OPERA are categorised in light of the UK National Institute of Health and Clinical Excellence (NICE)'s guidelines published in 2004, on the basis of i) the greater the number of relatives on the same side of the family with the same cancer or cancers that are known to run together; ii) the younger relatives were at diagnosis and iii) the more closely related to the person who is doing the assessment are. In light of this, OPERA invites users to enter details of their personal and family history of breast and/or ovarian cancer. It also gathers information on age, sex, ethnicity and history of other cancers that are relatively rare.

The user is led through the process by a series of questions about his/her demographic data and family history situation (e.g. *Have you ever been diagnosed with breast cancer?; In your family, how many relatives on the same side of the family have had breast and/or ovarian cancer?*).

As the user answers the questions, the engine determines which questions should be asked next, the level of risk (via a decision-tree) and how to tailor the final feedback according to Kreuter et al.'s model [1].

A number of rules determine the inner working of the engine. Rules have the conjunctive form, **IF** (A **and** B **and** C **and** ...) **IMPLIES**  $\alpha$ ; where ' $\alpha$ ' can be:

- a question number (determining if a question should be asked or not)
- a level of risk ('low', 'medium', 'high')
- a piece of information (determining if that piece should be delivered to the user or not)

"X" is an <attribute – value> pair, determined after each question has been answered. Attributes (and corresponding values) are used in order to represent the relevant data gathered, independently from the specific way to formulate a question or to characterize a possible answer.

The feedback delivered to users after the test comprises two basic elements, which are joined to formulate the information package, namely:

- *Summary*: a textual expression of the most relevant data to assure the correctness of users' answers
- *Risk assessment message*

For reasons that will be clarified in the following section, one of the main challenges in designing OPERA rested on the need of creating an 'appropriate' (persuasive) message for low-risk users. This paper focuses on how this message has been designed.

## 2 THE LOW RISK CATEGORY

The development team for OPERA was composed of the authors of this paper, together with the stakeholders in charge of Cancerbackup's initiative. Our primary goal was to design a tool to promote awareness of the risk level to women who are not at significantly increased risk of having a faulty gene in their family. This goal was in fact perceived by Cancerbackup as an important strategy to limit unnecessary demand of consultations and services.

Several sets of guidelines have been published which outline the approximate risk to relatives of developing inherited breast

<sup>1</sup> Institute of Communication and Health & TEC-Lab, University of Lugano, Switzerland, email: sara.rubinelli@lu.unisi.ch

cancer, depending on the strength of their family history of breast and ovarian cancer. All these guidelines, which differ on minor details rather than on any issues of important substance, concentrate on informing those individuals considered to be at high, or significantly increased risk. Indeed, these individuals may be offered access to genetic testing or to programmes of more intensive screening to identify early disease.

However, individuals who have what is considered to be a significant family history of breast cancer only constitute a small minority of all those who have some family history of breast cancer. The majority of women who have a relative with breast cancer are not at significantly increased risk of developing this condition. As a matter of fact, however, the evidence is that breast cancer has a particularly high political and media profile, and there appears to be a real, but probably exaggerated, fear of developing breast cancer in family members of women who have already had the disease. This situation provided an important opportunity to think carefully about how to structure communication to the low-risk people in ways that galvanize positive sentiments around this issue of genomics instead of stimulating stigmas.

### 3 TAILORING HEALTH MESSAGES: THE NATURE OF THE ARGUMENTATION

In the last few years, due to an increased availability of genetic tests and a growth in genetic counselling, the study of risk communication has produced several important contributions [2] [3]. Yet, although the issue of delivering information about cancer genetics according to people's level of risk has arisen in the literature [4] [5] [6] and, also, there are several studies on online genetics risk communication [7] [8] [9] [10] [11], the issue of how to address low risk people, as far as we know, has not been tackled. The choice of the general framework to be adopted by OPERA has been a particularly critical one. Indeed, the way a message is framed highlights some features of an issue making them salient (i.e. more meaningful and memorable) to an audience [12]. As particular features become more salient, the probability that an audience will perceive, process and store them in memory increases: frames impact on how people think about a topic and how they process topical information [13].

After a series of meetings with the stakeholders of the project - where we have mainly implemented the technique of directly asking experts for knowledge [14] and a content analysis of the letters that genetic counsellors write to patients [15], we established the main design criteria for OPERA's information packages, namely:

- The NICE's guidelines for the management of familial breast cancer form the evidence base for the entire programme.
- The claim indicating the level of risk, and the available management options, should make transparent the rules that lead to that claim being made. The programme should also offer broader supporting material (e.g. reference to medical literature, specific articles and, ultimately, the guidelines) and sources of personal support (e.g. details of helplines or places where the user may go for further explanation).
- The explanation should include a rebuttal, which aims to ensure that the user does not form an incorrect inference from the claim made.

- The explanation should contain an indication of the confidence with which the claim is made. In dealing with inherited cancer risk, in particular, it has to be clear that should the personal or family history of the user change, s/he would have to repeat the assessment.

The above features codified the importance of two main attributes of the message to be delivered by OPERA to the low-risk population, namely its argumentative force and the high level of tailoring.

As we have discussed elsewhere [15], these characteristics are indeed what distinguish OPERA from other similar applications in the field that are currently online.

By drawing on our previous research on the nature and role of argumentation in doctor-patient interaction [16] [17] [18], we looked for a theory of argumentation which could help us framing the message. We opted for an essentially deductive 'argumentation by association'.

The term argumentation by association goes back to the New Rhetoric [19] to indicate those argumentative moves where two elements that are separate in the mind of an audience are coupled in light of a certain (more or less) explicit relation. Considering that for the New Rhetoric there are different types of argumentation by association, we chose as the main frame for OPERA an argument by association on 'the structure of the reality' [19]. By using as premises 'facts' (propositions about reality that can be assumed without further justification, that in the context of OPERA contain data about users' personal history and the history of their families) and 'truths' (propositions that make connections about facts, in our case the NICE's guidelines) we designed a message where the main claims ('You are at risk X' and 'You should do Y') are presented as the effects of the premises, with a causal link aimed at guiding the audience from accepting the cause to the effect.

To quote an example, a user who gives the following answers:

*currently aged between 19 and 39, female, not had breast cancer, not had ovarian cancer, no men in the family who have had breast cancer, one female relative diagnosed with breast cancer when she was over 40, no Jewish ancestry, no history of some unusual type(s) of cancer in the family*

receives the following message concerning her level of risk:

*«Your answers suggest that it is unlikely that there is a faulty breast cancer gene in your family.»*

The reasons behind the risk-level are, then, presented by means of a tailored explanation based on the selection and combination of those attributes that are particularly relevant for supporting the diagnosis of low-risk in light of the NICE's guidelines. In the outcome, the explanation of the above risk is justified by pointing out the small number of relatives who have had a history of breast cancer, as well as the age of the development of the cancer, in the following format:

*«This is because you stated that you have only one female relative who had breast cancer and she was over 40 when the cancer was diagnosed. As you will see in the explanation below, the number of relatives with cancer as well as age at diagnosis are important factors when considering inherited risk of cancer.»*

In a second stage, we decided to include a dialectical component in the structure of the argument. Indeed, one of the key premises from which argumentation theory proceeds is that influencing real audiences is not simply a matter of presenting facts and premises which are scientifically validated. Very often it is important to take into account values, attitudes and opinions that people might have [20]. As recently discussed by Bennet et al [21], although the majority of people that undertake cancer genetic risk assessment based on family history employ a minimal emotional effort, about 25% show high level of distress. Main factors likely to influence an emotional response to a risk diagnosis include people's understanding of the nature of the health threat and their expectations of its outcome. The personalisation of one's argument appears, here, as a necessary requirement for the fulfilment of the maieutic function of a critical discussion. We considered this assumption to be particularly relevant in dealing with the low-risk group.

Indeed, people resulting in the low-risk category do not have a significant personal or family history. Yet, they must have a reason for utilising the program including the possibility that they perceive themselves in a higher risk category. This reason has to be addressed to prevent potential resistance to good news. The phenomenon of risk perception resistance is known in the literature. Studies have shown that women tend to overestimate the chances of getting breast cancer as a consequence of their overestimation of their risk [22]. This aspect becomes essential when users have reasons for using OPERA that go beyond an answer of the form «*You do not have any significant personal or family history*», primary based on underlining the absence of significant risk-factors.

To help formulate the question for assessing users' motivations, we screened possible sources of influence on people's risk-perception, considering what could have influenced the perceived threat of an hereditary cancer link.

By moving from a social-interaction perspective, we assumed that individuals' beliefs and opinions are the product of micro-individual characteristics and of a social construction activity performed within the social networks of the single person. According to this perspective, inter-individual perceptions and the content of these relationships have some influence on perceptions and behaviours. Following the indications by the stakeholders, who have years of experience with the concerns on genetics that people express to Cancerbackup, we have decided to consider three main possible categories of influence: 1) *Influence from healthcare workers*; 2) *Influence from relatives and friends*; 3) *Influence from the media*. In the outcome, we added a question at the end of the test for the low-risk group that enquires about the following sources of concern:

«*You decided to use Cancerbackup's OPERA because:*

- *You recently read or heard something in the media about cancer in families.*
- *One or more relatives have had breast or ovarian cancer and you are worried about yourself and/or other family members developing it.*
- *You have had breast or ovarian cancer and you are worried about your children or other family members developing cancer.*
- *A friend has recently been diagnosed with breast or ovarian cancer.*

- *Someone in the health service suggested that you use this program to find out about your risk.*
- *None of the above reasons.»*

The answer is then addressed in the tailored explanation. Thus, going back to the previous case, if the user declares concerns due to family history, he finds attached to the section of the message that justifies the level of risk the following sentence:

*«It is nevertheless understandable that your family history has caused you concern. The following information will hopefully help you to address your concerns.»*

The message continues by explaining how the risk is calculated and what aspects count into it:

*«The risk of breast and ovarian cancer being caused by an inherited faulty gene is assessed by considering your family history of breast and/or ovarian cancer. The following are all important considerations:*

- *The greater the number of relatives on the same side of the family with either of these cancers*
- *The more closely related they are*
- *The younger the age at diagnosis*

*Factors such as Jewish ancestry and some rare cancers developing at a young age are also taken into account.»*

The user is, at this point, expected to make the inference that the fact of having one only relative who has had breast cancer (and, moreover, over 40) is not significant enough to indicate any possible genetic link.

With the following section of the risk assessment, the low-risk person is advised on what to do next. Here, again, the argumentation has been constructed by making an explicit link between the attributes of the personal and family history of the person assessed and the available offer for testing by the National Health Service. Continuing the example we are exploring, the message presents the suggestions below:

*«If you are still concerned about breast or ovarian cancer occurring in your family, you should discuss your situation with your doctor. However, based on your answers to the questions in this programme, unless your family history changes or an exception is made, it is probably unlikely that you or members of your family will be offered genetic testing or extra screening on the NHS.»*

Overall, the personalised messages is manoeuvred between an essentially deductive argumentation, very close to the Toulmin's model of reasoning [15] [23] [24], and a more dialectical component that has a purely rhetorical goal.

We expect the main impact of OPERA to be based on users' evaluation of an appeal to expert opinion. Indeed, OPERA is thought to work on the recognition on two main premises. The focal premise is that the source of the message (i.e. Cancerbackup) is a genuine expert in cancer information. The second premise is that this source asserts propositions that address the clinical genetic history and the eventual concerns of the person being assessed.

The application of this argument scheme in the design of OPERA has been facilitated by a series of factors. More specifically, an argumentative structure like OPERA can be

instantiated only if it can answer to the critical questions that are appropriate when evaluating an appeal to expert opinion [25].

First of all, the institution acting as a source has to be recognised as an expert in the field. Given the national and international recognition of Cancerbackup, this aspect was less problematic.

Secondly, problems might arise when there is disagreement among several experts over an issue. When disagreement occurs, it is difficult for a layperson to arrive at a reasoned opinion or decision about the issue. Here, again, being OPERA based on the NICE's guidelines, the coherence of the body of knowledge offered is guaranteed. Doubts might arise on whether the program, being online, is used by non-UK people from countries that apply different national guidelines.

Another important factor is that the interpretation of the expert's opinion by the layperson has to be carefully guided. To be useful, an expert opinion has to be in a form that is clear and intelligible. But, especially in dealing with genomics, the jargon can be technical and resists translation into accessible layman's terms. We had to face the issue of how to transmit clinical guidelines to the lay people. With OPERA, we answered to this aspect by designing the wording together with genetic counsellors who have a live experience on the way people react to their words and their letters during or after consultation.

## 5 CONCLUSION

A considerable amount of research has been done on providing information on hereditary cancer risk, but little on targeting such information to low-risk people. In this paper we have addressed the use of argumentation as a means to personalize a low-risk assessment in the complex and currently topical domain of hereditary cancer risk. We have shown how, in a fundamentally diagnostic application such as OPERA, a deductive framework based on scientific knowledge and on the authority of the source, enriched so as to also take into consideration users' reasons for accessing the tool, is expected to meet their demand of information and influence an appropriate emotional and behavioral response. Clearly, the approach we offer in this paper rests on a main assumption: that people are sensitive and respond to a fundamentally rational argumentation. This is a crucial, but still unexplored, aspect to consider and evaluate when speaking about 'argumentation machines' [26] in the healthcare domain.

We can mention, at this point, that OPERA is currently under a pilot-study (with a sample of approx. 100 women) that will end in June 2008. In light of the results so far achieved, we anticipate that the program results to be successful in meeting the expectations of both those women who have used it to find out their own risk, and those who have simply looked for a confirmation of previous knowledge/diagnosis about their risk level. Also, the strength of OPERA is perceived as resting, indeed, on its essentially scientific environment and the straightforwardness of the guidelines it applies.

One focus of our evaluation will be to verify if the argumentative framework here presented is effective also with moderate and high risk users. In those cases, in fact, OPERA does not only have to break bad news about a possible genetic link, but has to enhance users 'to do' something about their own situation. We cannot exclude, at this stage, that in dealing with treatment choices (and not simply with 'avoiding action' as the low-risk population is advised to), a more dialogical message is needed.

With regard to this, one serious limitation of the argument model used in this current version of OPERA is that all knowledge in the program is stored as pre-compiled arguments. This is an

approach that has the clear advantage of being simple, but it presupposes an anticipation of all possible arguments. At this stage we have worked on the assumption that the authority of the scientific guidelines is sufficient enough for meeting users eventual emotional concerns. More complex argumentative structures, performing a higher level of dialoguing interaction with users, are difficult to implement. We are currently exploring how theories of argumentation based on the critical discussion of arguers – in particular, the pragma-dialectical theory developed by van Eemeren and Grootendorst [27] and current models of persuasion [28] - can advance theory and practice of this further phenomenon.

## ACKNOWLEDGEMENTS

We would like to thank Dr. James Mackay and Dr. Andrea Pithers for the work done together. Special thanks also go to King's Fund for having supported the creation of OPERA.

## REFERENCES

- [1] M. Kreuter, D. Farrell, L. Olevitch, and L. Brennan, *Tailoring health messages*, Lawrence Erlbaum Associates, Mahwah and London, (2000).
- [2] M. Fransen, R. Meertens, and C. Schrander-Stumpel, 'Communication and risk presentation in genetic counseling. Development of a checklist', *Patient Education and Counseling*, **61**, 126-33, (2006).
- [3] C. Julian-Reynier, M. Welkenhuysen, L. Hagoel, M. Decruyenaere, P. Hopwood, and CRISCOM Working Group, 'Risk communication strategies: state of the art and effectiveness in the context of cancer genetic services', *European Journal of Human Genetics*, **11**, 725-36, (2003).
- [4] C. Phelps, K. Platt, L. France, J. Gray, and R. Iredale, 'Delivering information about cancer genetics via letter to patients at low and moderate risk of familial cancer: a pilot study in Wales', *Familial Cancer*, **3**, 55-9, (2004).
- [5] E.A. Lobb, P.N. Butow, B. Meiser, A. Barratt, C. Gaff, M.A. Young, J. Kirk, G.K. Suthers, and K. Tucker, 'Tailoring communication in consultations with women from high risk breast cancer families', *British Journal of Cancer*, **87**, 502-8, (2002).
- [6] E.A. Lobb, P.N. Butow, A. Barratt, B. Meiser, C. Gaff, M.A. Young, E. Haan, G. Suthers, M. Gattas, and K. Tucker, 'Communication and information-giving in high risk breast cancer consultations: influence on patient outcomes', *British Journal of Cancer*, **90**, 321-7, (2004).
- [7] D.L. Baker, T. Eash, J.L. Schuette, and W.R. Uhlmann, 'Guidelines for writing letters to patients', *Journal of Genetic Counseling*, **11**, 399-418, (2002).
- [8] N.A. Green, 'Bayesian network coding scheme for annotating biomedical information presented to genetic counselling clients', *Journal of Biomedical Informatics*, **38**, 130-44, (2005).
- [9] N. Green, 'Representing normative arguments in genetic counselling', *AAAI Spring Symposium Technical Report*, 64-7, (2006).
- [10] M. Suka, and K. Yoshida, 'Health risk appraisal using internet technology', *Methods of Informatics in Medicine*, **44**, 310-4, (2005).
- [11] J. Fox J, D. Gasspool, and J. Bury, 'Quantitative and qualitative approaches to reasoning under uncertainty in medical decision making. In: S. Quaglini, P. Barahona, S. Andreasson (eds): *Proceeding of the 8<sup>th</sup> Conference on Artificial Intelligence in Medicine in Europe (AIME 2001)*. Springer-Verlag, Berlin, 272-282, (2001).
- [12] R. Entman, 'Framing: Toward Clarification of a Fractured Paradigm', *Journal of Communication* **43**, 51-8, (1993).
- [13] S.T. Fiske, and S.E. Taylor, *Social cognition* (2nd edn.), McGraw Hill, New York, (1991).
- [14] E.Reiter, and R. Robertson, 'Acquiring correct knowledge for natural language generation', *Journal of Artificial Intelligence Research* **18**, 491-516, (2003)

- [15] J. Mackay, P.J. Schulz, S. Rubinelli, and A. Pithers, 'Online Patient Education and Risk Assessment: project OPERA from Cancerbackup', *Patient Education and Counseling*, **67**, 261-266, (2007).
- [16] S. Rubinelli, and P.J. Schulz, 'Let me tell you why! When argumentation in doctor-patient interaction makes a difference', *Argumentation*, **20**, 353-375, (2006).
- [17] P.J. Schulz, and S. Rubinelli, 'Arguing for the patient. Informed consent and strategic maneuvering in doctor-patient interaction', *Argumentation*, Forthcoming (2008).
- [18] P.J. Schulz, and S. Rubinelli, 'Healthy arguments for literacy in health', *AAAI Spring Symposium Technical Report*, 86-95, (2006).
- [19] C. Perelman, and L. Olbrecht-Tyteca, *Traité de l'argumentation. La nouvelle rhétorique*, Presses Universitaires de France, Paris, (1958).
- [20] F. Grasso, A. Cawsey, and R. Jones, 'Dialectical argumentation to solve conflicts in advice giving: a case study in the promotion of healthy nutrition', *International Journal of Human-Computer Studies*, **53**, 1077-1150 (2000).
- [21] P. Bennett, C. Wilkinson, J. Turner, K. Brain et al., 'Psychological factors associated with emotional responses to receiving genetic risk information', *Journal of Genetic Counseling*, **17**, 234-241, (2008).
- [22] A.J. Dillard, K.D. McCaul, P.D. Kelso, and W.M. Klein, 'Resisting good news: reactions to breast cancer risk communication', *Health Communication*, **19**, 115-23, (2006).
- [23] S. Toulmin, *The uses of argument*, Cambridge University Press, Cambridge, (1957).
- [24] S. Rubinelli, D. Bolchini, P. Paolini, and P.J. Schulz, 'Designing tailored arguments in online riskassessment tools', *Proceedings of the 11<sup>th</sup> International Conference on User Modeling, Personalisation for e-Health*, 57-60, (2007).
- [25] D. Walton, *The place of emotion in argument*, The Pennsylvania State University Press, Pennsylvania, (1992).
- [26] C. Reed, and T.J. Norman (eds.), *Argumentation machines. New frontiers in argument and computation*, Kluwer Academic Publishers, Norwell, 2004.
- [27] F.H. van Eemeren, and R. Grootendorst, *A systematic theory of argumentation. The pragma-dialectical approach*, Cambridge University Press, Cambridge, 2004.
- [28] D. O'Keefe, *Persuasion. Theory & research*. Sage Publication, London, (2002).