

Chapter 2

Methodology for systematic literature research in
biomedical science communication

'Sociologists and engineers, living as enemies, do both believe at the end there will be a solution. One on the social level and one the technological level. What they do not want to exile is their dispute, which at the end makes it impossible to understand the world we live in.'

Latour (1994)

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- Sanden, M.C.A. Van Der and Meijman, F.J. (2004). Evidence based science communication: an essay. *Science Communication*, 25(3): 272-287.
- Sanden M.C.A, Van Der and Meijman, F.J. (2002). The need for crossing the borders of communication sciences: comparative communication science leads to new theoretical approaches for science communication. In proceedings PCST-7 Congress, Cape Town, 4-7 December, South Africa.

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Preface

This chapter consists of three parts: 1) rationale for transdisciplinary research comparing different fields of (communication) science; 2) systematic literature research design: evidence based science communication; and 3) different levels of comparison.

Within this study one can speak of a first order and second order comparison. The first order comparison is between different fields of (communication) science: health communication, medical psychology, and (medical)commercial advertising. These fields and their theoretical and practical success and fail factors are compared to the current theoretical and practical success and fail factors of biomedical science communication. Based on systematic literature research, a theoretical framework is synthesized from this comparative study. The most important elements of this model have been put into a questionnaire, which was given to communication professionals, policy and strategy professionals and professionals working in patient organisations. This forms the second order of comparison.

The method developed for this research could provide the basis for further structural theoretical deepening and broadening of biomedical science communication in particular and science communication practice in general.

2.1 Introduction: experimental design

The explorative descriptive research for this thesis is mostly based on a comparative systematic literature study. The method developed for the research of this thesis is partly obtained from evidence based medicine (Sackett et al., 2000). The theoretical developments in biomedical science communication are compared to health communication, medical psychology, (medical) commercial advertising. This way of synthesizing new insights on a theoretical level is called transdisciplinary or translational research (Latour, 1994). This forms the basis for developing a new method, inspired by the words of Locke et al. (1998):

There is no best type of research. There are only good questions matched with procedures for inquiry that can yield truthful answers.

The following parts of this section explain translational research and the scheme of comparison. The approach of the systematic literature search is described in the article on Evidence-Based Science Communication, which is incorporated in this chapter (Van der Sanden and Meijman, Science Communication 2004, 25(3): 272-287).

Multidisciplinary Research

There is a major difference between transdisciplinary and multidisciplinary research. Multidisciplinary research forms a suspension¹ in which the different disciplines work together but retain their uniqueness at the same time. The disciplines do not dissolve into each other. Transdisciplinary research finally becomes a clear solution,² probably with a different colour. The disciplines together have created a new clear solution. A new discipline originates from the others. For example, Wilson (1998) writes about what he called consilience. According to Wilson, a multidisciplinary problem like global warming can only be solved by using or developing transdisciplinary insights or theories which embrace the complexity of the green house effect. Using this example, Wilson shows the point in environment technology where environmental policy, societal values, and insights from biology come together. To reach this, according to Wilson, fundamental analysis is needed. The first question to answer regarding the research methodology is whether it is possible to translate theories or elements of theories from one field to another, for example from health communication to biomedical science communication. This might be a problem caused by other contextual, process, cognitive and affective variables that matters in biomedical science communication on predictive DNA diagnostics. Is it theoretically possible, however, to compare different theories from different levels (individual, mass communication) in order to synthesis a new theory?

Verdoes (2005) writes about the use of theories from fundamental physics to actually improve the theoretical insights into scarcity and rationality in economics. Verdoes' findings serve as a prelude to the design of our research. Central question in Verdoes' study - who did obtain his doctorate on an economical subject - is whether a perfect market can exist. He uses Heisenberg's theory of uncertainty in physical processes and quantum mechanical theories to grasp the complexity of his research question. Furthermore, as an argument for the possibility of synthesizing theories, Verdoes uses Gödel's Incompleteness Theorem, which states: All consistent axiomatic formulations of number theory include undecidable propositions (Hofstadter, 1999). According to Verdoes, this is a meta-restriction on theories, since there is always a part of the problem to be investigated which is not included in the theory.

¹ In chemistry a suspension is a solution of at least two components, in which at least one component does not dissolve.

² In chemistry in a solution all the components (at least two) are dissolved.

Just as market and consumer aspects are central to Verdoes's research, in the field of biomedical science communication for predictive DNA diagnostics, aspects such as structure, process, outcome and context form the starting point for complexity and uncertainty. Meanings, notions, expectations and interests become distorted between the different variables and actors on a psychological level, a socio-psychological level, and on a social level (this can be called 'miscommunication'). In other words, as described in Chapter 1, in the biomedical science communication system complexity and uncertainty are multi-leveled.

By exploring different disciplines and their theories which are in the first place theoretically connected by Gödel's theorem, and on the second place by a meta-question on effective communication, we gain insight into uncertainty and complexity on different levels for effective biomedical science communication on predictive DNA diagnostics. This is a process of triangulation.

To reach certainty, one needs more than one theory. The comparison carried out in this thesis eventually will lead to a new and accurate theoretical framework (which also contains uncertainty, of course) towards effective biomedical science communication. This theory will probably be more accurate because its design contains more different levels and purposes. Essentially, this theory considers the loops Verdoes wrote about:

Don't the loops - which can change problems - form the core of economics? This study seems to keep circumventing the core, but this 'circling' actually is, or forms, the core. The hard core of economics is fragile. Theory can be viewed as optimum decision and as statement about reality. To what extent do these 'worlds' coincide? Is there evidence of an a-rational world, is economics an efficient description of an a-efficient world, or is the reverse true?

Given the uncertainty and complexity on different levels (sender, receiver and process) and the proposition that no theory can embrace all complexity and uncertainty by itself (Gödel's theorem), we can conclude that one needs more than one theory from different fields and viewpoints to understand uncertainty as well as possible. As Verdoes states:

The cross-discipline, underlying framework that has come into view by introducing variations in two ways provides opportunities for creating links between different insights.

This idea and the idea that theories are always connected on a meta-level as suggested by Gödel's work is the rationale for comparing different fields of communication science. As mentioned, two orders of comparison were used: first order, comparing literature, and second order, practical validation.

2.2 First order of comparison

The first order of comparison is comparing the literature on health communication, medical psychology and (medical) commercial advertising. First, the literature searched was divided into so-called consolidated literature and unconsolidated literature. The consolidated literature includes textbooks and handbooks, and the unconsolidated literature articles in scientific journals.

For every field of comparison, two experts/researchers were consulted to know which publications and which developments were most important to their field of research. Of course the choice in literature and the consequences from this choice are our responsibility. For practical reasons, the 10 most relevant or recent textbooks of every field were read, and the 50 (Chapter 3), 40 (Chapter 4) and 30 (Chapter 5) most relevant articles. This decrease in number of articles is an element in developing an instrument for quick use of new literature in developing evidence-based effective biomedical science communication. Since searching and

validating articles is time consuming, the question is: is a critical amount of valid and relevant information still found when the number of articles is reduced? The goal is to develop an instrument which is manageable, and optimized both in terms of time and communication goal. Both books and articles were searched on face value by the title of the book or article and abstract when available. For example, for Chapter 3 about 150 articles were checked by reading the abstract. In every chapter, the tables containing the results for consolidated and unconsolidated literature give examples of relevant and checked books and articles, as well as irrelevant ones which were not checked.

The most relevant literature was scored with (+++), less relevant with (++) and (+). After reading the books, not all of them turned out to be relevant, and only those which were judged relevant were used in the chapters analysis. The relevance was scored using 7 criteria (see Science Communication article in this chapter) developed by Meijman (1993) and Meijman and De Melker (1995). When the quality of the article met 6 or 7 criteria of relevance, it was scored (+++). When it met 4 or 5 criteria, the article was scored (++) and when fewer than 4 criteria were found, the article was scored (+). Non relevant articles (-) are not depicted in the chapter's tables. When criteria were not clear, a (?) was placed, and for precautionary reasons this was read as a negative score. For example, when comparing two articles which scored (++) and (+), the first would be considered slightly more relevant than the latter.

Furthermore, the articles were checked for validity. Validity was also scored with (+++), (++) and (+), based on 10 criteria developed by Meijman and De Melker (1995) (see Science Communication article in this chapter). When 9 or 10 criteria were met, the article was scored (+++), when 7 or 8 criteria were met, it was scored (++) and when 6 or 7 were met, (+). When 6 or fewer criteria were met, the article was marked as not valid (-). When the research method was not clear or not known, a (?) was used, and for precautionary reasons read as a negative score (-). Once again, for an article with equal relevance scores (+), the one with more (?) was recognized as more valid. This (?) sign, indicates that the reviewer could not definitely validate the article due to a lack of methodological knowledge.

Highly relevant (+++) and highly valid (+++) literature has the best convincing power (Meijman and De Melker, 1995). Such an article generates a stronger evidence-based element in the research's conclusions than an article with less convincing power. The conclusions of every chapter mention the level of relevance, the level of validity and the convincing power of the reviewed articles.

After the literature had been read and validated, it was categorized according to structure, process, outcome and context. In each of these categories success and failure were distinguished: the elements read in the validated literature which could be considered as positively contributing to an effective communication process and those which could be considered be negative and therefore better avoided.

In the medical domain, the Cochrane Library contains review articles with strong convincing power. Therefore these systematic reviews are used as the basis for the evidence based practice in that field. The Cochrane Library was consulted for Chapters 3, 4 and 5. Unfortunately, the articles were generally not relevant to the research questions of this research.

The fragments of the literature which were considered as the most important (relevant and valid) are included in the text in Chapters 3, 4 and 5 (they can also be found in the literature tables on the thesis's website: www.bscca.tudelft.nl).

Only literature written since 1980 was considered. Though this is an arbitrary choice, a few authors state it is only since the early 1980s that it has been expected that genetic engineering would become a strategic technology for the twenty-first century (Bauer, 2002). This forms the first order comparison between the different communication fields (see Fig. 2.1).

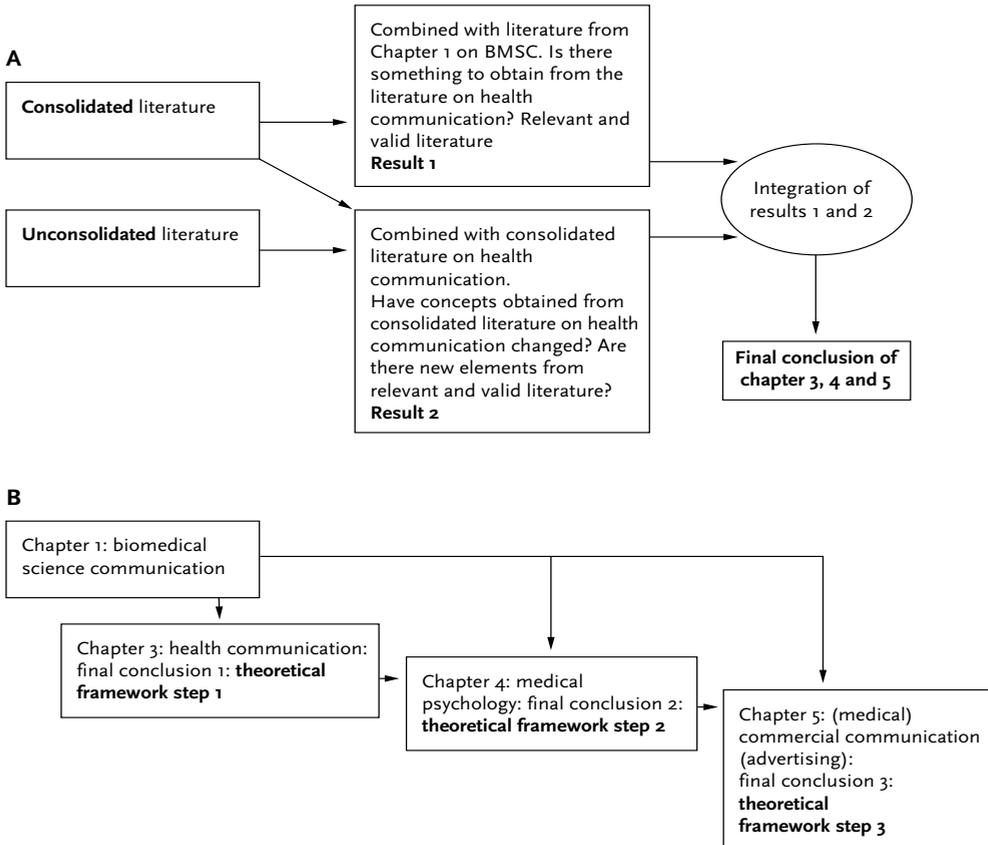


Fig. 2.1: A: First order literature comparison. The consolidated literature that was read is compared with the description of biomedical science communication (BMSC) from Chapter 1: result 1. The consolidated literature is then validated with the unconsolidated literature: result 2. Then conclusion 1 is integrated with result 2: have the concepts changed? Does the unconsolidated literature contribute new elements? (result 2). This eventually leads to a final conclusion. B: All the conclusions of the different chapters are linked to each other. The framework in Chapter 5 is a newly synthesized and valid translational framework, with systematic convincing power.

Every chapter ends with a theoretical framework, which has changed compared to the one in the previous chapter. So the framework in Chapter 3 is based on health communication; this is combined with insights from medical psychology to produce the framework in Chapter 4. Finally this combined framework is changed by insights from (medical) commercial advertising in Chapter 5. This makes the final theoretical framework a real translational model in which different fields of science melt together.

Of course this approach does not guarantee that there is no other (more relevant or more valid) framework to be found. However, this method makes it clear how literature is searched and used. This makes the method of systematic literature research much more transparent, since the choices in literature research are explicit. The literature for comparison is searched and validated using a method developed from evidence-based medicine leading to evidence-based science communication. The following article, Evidence-based Science Communication: An Essay. *Science Communication*, 25(3): 272-287 makes the criteria clear, as well as the sources for comparison. The results of a small study on systematic literature research are also described. The comparison for all three fields is carried out in the same way.

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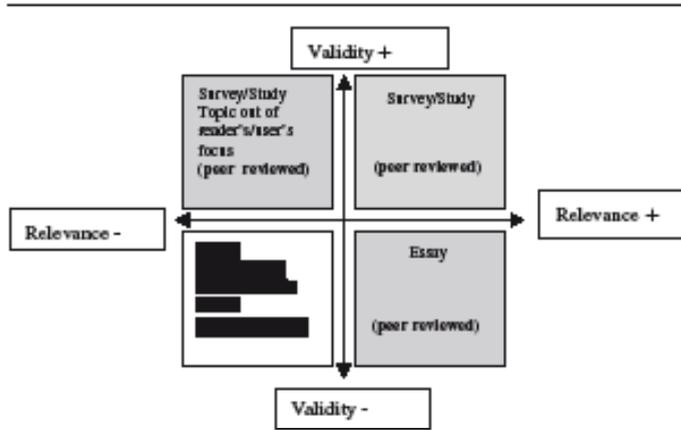
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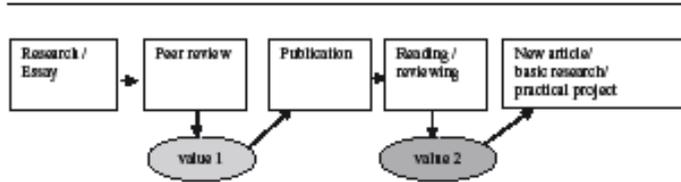
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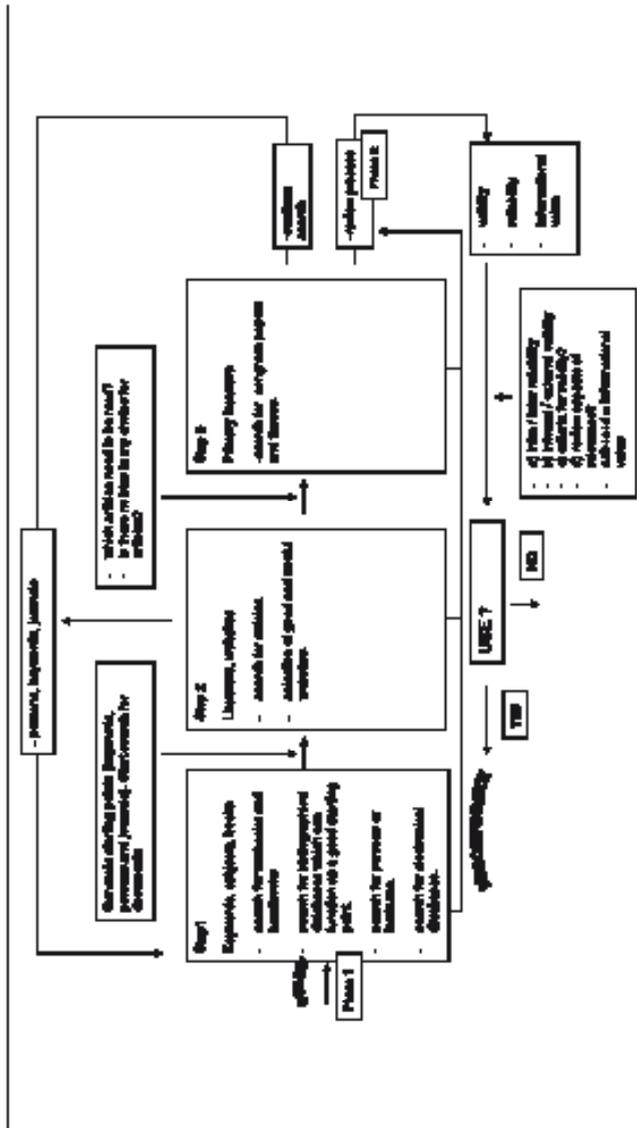
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2.3 Second order of comparison

A questionnaire was developed based on the theoretical framework for biomedical science communication for predictive DNA diagnostics as developed from the results of Chapter 3, 4 and 5. After it had been completed, the results were discussed in a group meeting. This second order of comparison had two aims: 1) to test the practical and theoretical relevance of the framework; and 2) to study the distance between theory and practice in effective biomedical science communication. The questionnaire differentiated three steps: 1) problem analysis; 2) synthesis; and 3) strategy and intervention. The questionnaire was given to the following groups (the complete questionnaire - in Dutch - is available on the thesis website):

- o communication professionals in the field of health communication (on genetics)
 - Koningin Wilhelmina Fonds (KWF): a foundation which financially stimulates cancer research and which is responsible for public cancer prevention campaigns;
 - Kiesbeter.nl: a website which is funded by the Dutch government to assist the public in making medical and health choices;
 - Centre for Society and Genomics (CSG): a foundation which aims to be a leading centre for understanding and stimulating the interaction between society and genomics.
- o representatives of patient organisations
 - Erfocentrum: a foundation which produces brochures and maintains websites on genetic diseases;
 - Nationale Patiënten Consumenten Federatie (NPCF): a federation which can be consulted by health and medical consumers for information and advice.
- o research and executive specialists
 - VUMC/Community Genetics: Community Genetics is about the application of medical genetics in the population. The research aim of Community Genetics is to maximize the benefits of genetics and minimize the negative effects;
 - GGD Amsterdam / Cluster Epidemiologie, Documentatie en Gezondheidsbevordering: involved in the development and execution of screening programs;
 - Rijksinstituut voor Volksgezondheid en Milieuhygiëne (RIVM): provides advice on different population research projects, also those concerning screening for genetic diseases.
- o policy and strategy professionals
 - College Voor Zorgverzekeringen (CVZ): CVZ guarantees and develops public critical conditions for national health insurance in order to make health care accessible for all citizens;
 - Het Nationaal Instituut voor Gezondheidsbevordering en Ziektepreventie (NiGZ): advises local and national health services and the national government on their public outreach programmes on health issues.

This selection of respondents represents the different phases of the development of a biomedical science communication process from the perspectives of communication process execution and development, screening policy making, and research on screening programs. If one develops a communication process for a screening program, one needs research information on the subject, to know the way the programme is to be executed, organisation goals of the screening programs, and how to develop a communication process. Each of these respondents has their own wishes and constraints when it comes to the development (or design) of an effective biomedical science communication process. If a questionnaire (and therefore the theoretical framework supporting the questionnaire) is to bridge the gap between theory and practice, it has to incorporate these wishes and constraints at an optimal level. Therefore, these different involved groups were questioned individually to understand their wishes and constraints regarding a questionnaire for effective biomedical science communication based on a theoretical framework. They were questioned in a group meeting to determine which elements of the questionnaire and theoretical framework provided the most consensus.

The following protocol was used:

- o Phase 1: In an interview by telephone, we asked about the state of the art of communication changes and problems (see website for questionnaire);
- o Phase 2: The respondent completed a questionnaire concerning a given case (screening on lung cancer);
- o Phase 3: The respondent was interviewed by a professional interviewer from CVO (Centrum voor Verslavingsonderzoek). During the interview (also developed with the help of CVO), which consisted of 119 questions (see thesis's website), the respondent was asked if the terms and theories used in the model were comprehensive and useful. The respondents were also asked if they would leave terms and questions out or add others. In a second part of the interview respondents were asked to fill in the questionnaire making use of their own case. This provided insight into the level of specificity of the model developed from the literature.

The overall results of the test were discussed in a group meeting (chaired by the CVO interviewer). This completed the Rapid Assessment method. In Chapter 6 the results of this test are discussed. This discussion forms the input for changes in the theoretical framework.

The meeting which was attended by representatives of all the groups of respondents was designed as follows (see website thesis for programme and introductory presentation):

- o The results of the questionnaire are added to the framework, and a series of questions for further research are derived from the questionnaire.
 - Guided by a CVO-member, the group discussed the different changes in the framework.
 - Points abstracted from this discussion and the research questions were discussed:
 - Which theoretical changes should be studied?
 - Which practical changes should be studied?

Based on the first and second order comparison, it is possible to formulate a final theoretical framework towards effective biomedical science communication and a research agenda for the future, both of which are presented and discussed in Chapter 7.

