

# Chapter 7

Conclusions, discussion and future research

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## 7.1 Introduction

The main aim of this thesis and explorative descriptive research was to investigate which variables related to the structure, process, outcome and context of the communication process, obtained from health communication, health psychology and (medical) commercial communication (advertising), could help in assembling a theoretical framework for an effective process of biomedical science communication on predictive DNA diagnostics. This framework is needed to support the practice of biomedical science communication in an effort to develop effective communication processes.

This aim originates from the observed problem that neither existing concepts, theories, models, constructs and variables such as described by Miller and Kimmel (2001) on biomedical science communication and science communication, nor their historical background, support a sufficient body of knowledge to develop a profound theoretical framework for biomedical science communication. We have systematically analysed the consolidated and unconsolidated literature (chapter 2: methodology for systematic literature research) on health communication (chapter 3: the main difference in domain compared to biomedical science communication), health psychology (chapter 4: the main difference at a theoretical level compared to biomedical science communication) and commercial communication (chapter 5: the main difference in communication function compared to biomedical science communication). Various concepts, theories, models and constructs obtained from these fields were used to build a theoretical framework for the field of biomedical science communication.

We chose medical developments in predictive DNA diagnostics as a case and context for the communication process. A context is needed, as chapter 1 makes clear. Later on in our research we assert that nothing in communication makes sense except in the light of context. Moreover, insight into biomedical science communication challenges is urgently needed due to the rapid and far-reaching development of predictive DNA testing and its impact on the lives of individuals and on society as a whole.

We based the theoretical framework for effective biomedical science communication on the many constructs and variables obtained from health communication, health psychology and commercial communication. It was tested in practice as a questionnaire (chapter 6) in order to understand the degree of distance between theory and practice. We asked ourselves if, by comparing health communication, health psychology and commercial advertising with biomedical science communication, we had built a framework that is still relevant for the practice of biomedical science communication on predictive DNA testing.

From the test of the questionnaire as described in chapter 6 we are able to conclude that we have built a theoretical framework and a questionnaire that make biomedical science communication on predictive DNA diagnostics both understandable and manageable. The theoretical framework as such may form a theoretical basis for a model for effective biomedical science communication in the future, since we did not test its effectiveness by - for example - comparing its implementation with other existing interventions. We have tested its relevance for biomedical science communication practice.

Though there are many concepts, theories, models, constructs and variables described in this thesis, as previously stated, we focused primarily on the level of constructs and variables: constructs such as self-efficacy and internal locus of control, and variables such as emotional distance and expectations. In section 7.4 (future research) the need for a clearer view of these analytical differences is discussed. This section depicts the different angles that could be used to research effective and manageable biomedical science communication. However, these angles are still somewhat vague, due to the lack of a contextual theoretical framework. We are currently building such a theoretical framework.

The theoretical framework and the questionnaire abstracted from it are new to the field of biomedical science communication in particular and to science communication in general. In the following sections we draw several conclusions, reflect on and discuss research constraints, future research and the role (theoretical and practical) of biomedical science communication in predictive DNA diagnostics.

## 7.2 Conclusions

We start with an overall view of the conclusions followed by answering the research questions from chapter 1 and end with conclusions on structure, process, outcome and the context of the biomedical science communication process. In answering the research questions, questions 2 and 4 are taken together.

### Overall

Concepts, theories, models, constructs and variables relevant to the domain of biomedical science communication were taken from health communication, health psychology and commercial communication and used to build a theoretical framework for manageable biomedical science communication on predictive DNA diagnostics. As previously stated, the comparison was most frequently made at the level of constructs and variables. From health communication, which differs in domain from biomedical science communication, we learned the differences in levels of urgency and importance according to each target group. Moreover, we obtained many socio-psychological constructs and variables from the main concepts, theories and models of health communication. Health psychology, which differs at a theoretical level, was relevant in generating new concepts, theories and constructs and ways of intervention which were not part of health communication. From commercial advertising we learned that the function of the communication process is an important factor to take into account, for there might be differing moral or ethical constraints. Aims, policies and strategies that are common in commercial advertising might not be ethically justifiable in the case of biomedical science communication on predictive DNA diagnostics. Insights obtained from commercial communication support the idea, obtained from health communication and medical psychology as well, that on a short and midterm basis factual and other substantive content of information is of lesser importance in effective biomedical science communication with a lay audience than the contextually determined and emotionally perceived 'meaning' of the information. The conclusions obtained from these systematic analyses of health communication, health psychology and commercial communication formed the basis for a theoretical framework to make biomedical science communication on predictive DNA diagnostics understandable and manageable. From this model we developed a questionnaire to determine the difference between theory and practice. Surprisingly, this has led to the development of an instrument to assist communications professionals in developing biomedical science communication processes. This was surprising because the instrument was developed to test the distance between theory and practice in order to gain insight into the relevance of the theoretical framework, and was not originally intended to be an instrument for communication practice.

### Research questions

Main research question:

*Which variables related to the structure, process, outcome and context of health communication, medical psychology and (medical) commercial communication (advertising) are relevant and useful for building a theoretical framework for effective biomedical science communication on predictive DNA diagnostics?*

Analysing the relevant literature as described above seriously strengthen biomedical science communication on predictive DNA diagnostics in terms of structure, process, outcome and the awareness of context. Most of the constructs and variables raised in this research are relevant to articulating more specific questions for the theoretical and practical challenges of biomedical science communication. The findings in this thesis contribute to the broadening and deepening of the theoretical frameworks from models developed by Miller and Kimmel and by Van der Auwaert, described in chapter 1.

Some of these constructs and variables are immediately useful in the domain of biomedical science communication (i.e. self-efficacy, health locus of control); others form a platform for rethinking and expanding upon or restricting the options for biomedical science communication (i.e. the ethical constraints of the use of theories from commercial advertising). Our results regarding the elements of structure, process, outcome and context are described below.

The newly formed theoretical background as well as the position pave the way for new research questions for biomedical science communication in the future, on predictive DNA diagnostics in particular, and on science communication more generally. These will be discussed in section 7.4.

#### Sub-research question 1:

*Which variables play a crucial role in the structure, processes, outcomes and contexts of effective health communication, effective medical psychology and effective (medical) commercial communication (advertising)? How might they contribute to the theoretical framing of biomedical science communication on predictive DNA diagnostics?*

### Structure

On the element of structure there is much to be found in the communication fields we explored and compared to biomedical science communication. We can distinguish two levels of structure: 1) the communication process between science communication researchers and science communication professionals; 2) communication between science communication professionals and a target group. From health communication in chapter 3 we learned that a 'research liaison officer' is of importance for a manageable communication process between research and practice.

For the communication between professionals and a target group we have learned from medical psychology that there must be a low-threshold service provided to patients and the public. This means the availability of time. The information officer (i.e. communication professional) must be less scientific in his approach, and there must be a possibility to return to get more information. From commercial advertising we learned that the message between a professional and a target audience consists of different elements, such as scene, event, programme, visual elements and other elements (i.e. affective elements) that are not directly relevant to the issue. Also, the cognitive level (i.e. level of knowledge use, knowledge growth and notions of knowledge) of the message and the kind of message are variables to take into account. In the literature on medical psychology and health communication, surveys have shown that so-called tailored messages are considered to be the most effective.

In summary, the structure of the biomedical science communication process on predictive DNA diagnostics can be supportive of manageable biomedical science communication by: 1) building bridges between communication researchers and communication professionals; 2) providing easy access to the communication process for the target audience by offering low-threshold services and tailor-made messages in which elements such as event, scene, and issue-irrelevant information are customised to the target audience.

### Process

In chapter 3 social psychological theories and models such as the Health Belief Model (HBM) and the Protection Motivation Theory (PMT) were introduced. Models for planned communication actions were introduced as well. One of the main examples of such a planning model is the Precede-Proceed Model (Green and Kreuter, 1991). With these social psychological theories and models and models for planning, constructs such as self-efficacy and health locus of control were introduced into the domain of biomedical science communication. Also, new modalities and aims obtained from the domain of health communication were introduced to the field

of biomedical science communication: biomedical science promotion, biomedical science education and prevention of biomedical knowledge deprivation. These modalities, together with aims such as PES (public engagement of science), PAS (public awareness of science), PUS (public understanding of science), and PPS (public participation in science) and effects of science communication enlarge the scope of possibilities and generate more questions about the biomedical science communication process at both the theoretical level and the practical level. As many respondents to the questionnaire stated, the theoretical framework does help to articulate questions and to generate awareness of the possibilities and risks involved in the use of different models. This helps the biomedical science communication process to become more manageable and, perhaps, more effective in the future. Therefore, its effectiveness should be tested in the future. Taken together, one can conclude that on the theoretical level the diagram described by Van der Auweraert and modified by us in chapter 1 becomes more complex and dynamic when the new information obtained from our research, such as the difference between modality and aim, is added.

From medical psychology we have learned that asking questions is an effective way of involving an audience in the communication process and in the organisation process. The questions asked and the answers given are built on theories that describe the different target groups (distancers, acceptors and pragmatists) and their different needs for information. These different needs lead to a communicametric description of the process. From this description the different phases of the biomedical science communication process can be easily distinguished. Newly added constructs are compliance and empowerment.

When we examined commercial advertising we constructed the image of a pair of scales with many communication aims and levels. One of the main insights obtained from this pair of scales is that information is a variable that is of minor importance within an effective communication process as noted by different surveys. It should not be overestimated. Regarding the aim of the communication process, insight into lay knowledge, basic notions, cultural themes and other contextual aspects are important (see section on context below). These findings are of use to the concept of transaction as described in chapter 1. However, one must keep in mind that transmission and transaction can co-exist. Another important addition to the domain of biomedical science communication from commercial advertising and supportive of the difference between transmission and transaction is the use of the Elaboration Likelihood Model (ELM).

This theory contains one of the most striking new insights from commercial advertising, in which issue irrelevant information plays an important role. Based on the ELM, two different pathways of information processing are possible: a central and a peripheral route. Both routes lead to a change of attitude for a target audience, however the way to this change is different. The central route is the route in which knowledge is consciously evaluated by the target audience. The peripheral route involves the evaluation, consciously or unconsciously, of more emotional elements. The routes could play a role in both transmission and transaction, of the biomedical science communication process though time and phase would lead to the accentuation of different elements.

When it comes to the use of the theoretical framework in practice the test has shown that with respect to process, communication professionals want to start with a description of the aims of the communication process, whereas policy and strategy specialists start by describing the audience. So in practice there is a difference to be seen in a sender-oriented and an audience-oriented way of structuring the biomedical science communication process. Also the constructs and variables depicted in the test are situated in this respect. This means for example that variables such as notions of knowledge on the part of the lay audience are not evaluated in first instance by communication professionals and therefore tunnels the focus on the target audience by communication professionals who begin by thinking about the organisations goal. This may lead to miscommunication.

From the theories obtained the process of biomedical science communication as described by Miller and Kimmel and by Van der Auweraert can be broadened and deepened, and research questions for the future can be more precisely articulated, not only from a theoretical perspective but also from a practical perspective. In summary, the process of biomedical science communication can be profoundly analysed by using the various models, constructs and variables obtained. These could also be used to design a manageable strategy for biomedical science communication.

## Outcome

Descriptions of the outcome of the health communication process, medical psychology and commercial advertising are rather different. However, one of the similarities in developments comparing these domains is the trend toward two-way communication and interactivity, emotions, meaning and awareness on the subject. This means, for example, that information is of less importance when a target group is far removed from the subject.

As described in chapter 1 and in the section above on process, in science communication in general there is a paradigm shift away from transmission to transaction, a shift in which connecting to the capacities and competences of a target audience becomes more and more important. To connect to the existing capacities and competences or to develop the capacities and competences of the target audience the known modalities, aims and effects of biomedical science communication should be evaluated in terms of this concern. The question is how to connect the sender's modalities and aims such as PAS, PUS, PES and PPS with effects on the recipients, such as awareness, understanding, opinion, interest and enjoyment, change of knowledge, expectations, participation behaviour and its sustainability, and knowing what biomedical science really is? The theoretical framework and the questionnaire we developed raise these kinds of questions and therefore generate insight into what is understandable and manageable within the biomedical science communication process. For example, on the level of the enhancement of self-efficacy, to seek information or ask questions on predictive DNA diagnostics.

This again broadens and deepens the models of Miller and Kimmel and of Van der Auweraert (2003). Even the knowledge paradox mentioned in chapter 1 might not exist or would have to be described differently while science communication has so many affective aims in addition to informational ones.

## Context

Context was added in this thesis to the analytical tool of Donabedian (1980) in which structure, process and outcome were described. From the introduction we have already learned that context is of main importance to the process of biomedical science communication. And as we stated in chapter 5: 'Nothing in communication makes sense, except in the light of context'. This context is formed by cultural themes and notions and by societal developments that are a result of scientific and technological development.

In the pair of scales described in chapter 5, notions and cultural themes are the main variables in consumer behaviour, and information is of lesser importance. Aspects such as high and low involvement are based on this principle and are introduced to the domain of biomedical science communication. All of the chapters make it clear that at least 80 percent of the communication process with (for example) a moderately involved audience depends on contextual and emotional aspects. This makes transmission and transaction highly complex strategic elements for which researching variables such as self-efficacy, high- and low-involvement, motivation, knowledge locus of control, issue-relevant and issue-irrelevant information is needed. The focus on the influence of context on the communication process fills in an insight missing from the models of Miller and Kimmel and Van der Auweraert.

As summarised for structure, process, outcome and context, we began with models from Miller and Kimmel and from Van der Auweraert, with perspectives such as the democratic perspective, general science communication goals such as public awareness of science, the idea of two-way communication and the operationalisation of a difference between transmission and transaction. From this research we added the idea that information is of lesser importance to the biomedical science communication process, that notions and cultural themes are of main importance, three communication modalities of which biomedical science promotion is one, the idea of research liaison officer, constructs such as self-efficacy and knowledge locus of control, the idea that asking questions is much more important to the residual audiences, communicametrics and systems theory, and emotional distance. From all this we built a theoretical framework. Moreover we added

an instrument that makes the biomedical science communication process on predictive DNA diagnostics more understandable and manageable. Effectiveness is still to be tested. We also generated insight into the position of biomedical science communication in accordance with other knowledge domains. All these items open many new means of investigation in the domain of biomedical science communication and deepen and broaden the models of Miller and Kimmel and Van der Auweraert.

This means that within the different biomedical science communication modalities, such as promotion, education and prevention of knowledge deprivation; the different aims, such as PAS, PUS, PES and PPS (in which the vocabulary of science and technology, knowledge of the impact and insight into the process are important); and the different effects, such as awareness, enjoyment, opinion, understanding, many different accents are possible. In other words, insights into the variables enlarge insight into the many possibilities, the interrelatedness and accents of variables and the dynamics of the process of an effective biomedical science communication process.

From the methodological point of view: in chapter 3 we learned about the different constructs and variables (health communication as an other domain). In chapter 4 (medical psychology as an other theoretical level) we learned how these constructs and variables are interrelated, which are the most important, and their possible sequence. In chapter 5 we learned about the different sequences and alternative routes while adding extra constructs and variables (commercial advertising as an other function). Moreover, information is not always of utmost importance.

#### Sub-research questions 2 and 4:

*Is it possible to build a valid framework for effective biomedical science communication on predictive DNA diagnostics from the results of this comparative study? And when analysed from theory is this realistic from a practical perspective? In other words, what is the distance between theory and practice?*

All the constructs and variables described above and differentiated to structure, process, outcome and context were used in building a theoretical framework as described at the end of chapter 5. This framework is valid in its manageability but this does not automatically mean that the framework is effective as well.

From this framework a questionnaire (as described in chapter 6) was developed. Surprisingly, the respondents recognised this questionnaire as an instrument for assembling biomedical science communication policy and strategy but less as an instrument to use during daily practice. It turned out to be an instrument that helps to articulate questions and risks when used in a group of trained communication professionals. It is an instrument for planned thinking and working - communication professionals may use the instrument to support their thinking on biomedical science communication. In return for this service, when applied in practice, the data obtained from the communication professionals could be used to improve the instrument. As such the instrument is self-referential and a laboratory instrument for biomedical science communication research. Together with an easily available and accessible database of systematically analysed literature on biomedical science communication for communication professionals, as described in chapter 5, the instrument bridges theory and practice. The idea of the literature database is based on the same ideas as those behind the Cochrane Library. But all of this still does not prove the framework leading to effective biomedical science communication. Therefore survey research is needed.



## Sub-research question 3:

*What is the position of biomedical science communication within the communication domain?*

In addition to the main research question, the question on the position of biomedical science communication in relation to the other domains of communication is also important. For example, is biomedical science communication a modality as such or is it an aspect within - for example - health communication? Or, is health communication an aspect of biomedical science communication? The answer to this question is important for direct or indirect theory and instrumental use in practice.

In chapter 1 we began with the description in which biomedical science communication is most relevant when it is about communication on biomedical science developments with a target group that is not directly involved. By comparing the different communication domains and a biomedical science communication related field such as health psychology, we concluded that there are three aspects that are crucial to establishing which communication modality (health communication, commercial communication or biomedical science communication) is needed at a particular time: 1) the context; 2) the communication aim and; 3) the emotional distance between the target group and the communication subject (predictive DNA diagnostics regarding this thesis). When the context of the process does not demand the involvement of a target audience into biomedical science developments in terms of urgency, one should choose biomedical science communication as a communication domain to reach the target audience. And when the target group is not involved due to substantial emotional distance, the communication aim is to raise awareness, because convincing or giving information as a communication aim is not desirable for ethical reasons. Of course a communication professional may use elements from health communication but primarily the chosen communication instruments are based on biomedical science communication.

The main difference between biomedical science communication and health communication is the difference in emotional distance on the part of the public. Health communication constructs and variables such as fear, hope and compliance operate in a different light when one's own health, or that of a close relative, is concerned than they do in contexts in which one's own health is not at stake. For example, if a new genetic test is to be discussed with a not-yet-involved lay audience this is more like biomedical science communication. When there is a need and/or urgency for the test to be used on an individual or a group, we are dealing with health communication. In both domains one can develop a public campaign, but the angle of the message is different. In practice both fields should be more interrelated and start from the context of the communication problem. Over time, when an individual or a group changes from non-patient to not-yet-patient, the communication process changes from biomedical science communication to health communication. Therefore the border between health communication and biomedical science communication is permeable. From the moment you choose your target group and decide on which issue or domain you are going to communicate the rest of the variables, modalities and sequence become more clear: nothing in communication makes sense, except in the light of context.

The difference between commercial communication and biomedical science communication is more evident in an ethical dimension. When it comes to persuasion on an emotional or cognitive level there is much to be learned from commercial communication theories but there are of course differences on the product level. The use of the Elaboration Likelihood Model (ELM), for example, strengthens the biomedical science communication process by emphasising the use of irrelevant information as an effective communication strategy. From commercial communication, in which the ELM is used, we learned about 'step by step timing' and the use of issue-relevant and issue-irrelevant information. This generates no ethical problems when it comes to a new kind of aftershave, for example, but does make a difference when it comes to predictive genetic testing. Societal developments such as medicalisation and genetic essentialism, as described in chapter 1, come into play. And this specific context ethically binds the use of theories, concepts and models obtained from commercial communication.

So biomedical science communication may be less constrained in its use of health communication theories than when it comes to using theories obtained from commercial communication. Therefore, theories from health communication and science communication could be more up-regulated and theories from commercial communication should be more down-regulated for use in the biomedical science communication domain. This insight is of use when new theories, which are beyond the scope of this thesis, are to be incorporated in the domain of biomedical science communication. Of course all of this depends on the aim of the biomedical science communication process.

This means that the difference between domains of communication is formed by the context of communication instead of by theories or the practical use of theories. Therefore the translational use of theories and instruments should always be considered from the context of the communication process at stake, rather than only from the structure, process or outcome of the communication process.

When it comes to the position of biomedical science communication among the other fields of communication, we conclude that the sort of communication is completely dependent on the context of the communication problem, the phase of development the problem is in and the emotional distance of the target audience to the problem. As we have argued in this thesis one may start with instruments and planning regarding biomedical science communication and end with health communication. Or, one may start with more commercial advertising techniques within the field of biomedical science communication and end with health communication. There are many possibilities. Moreover, within these possibilities the different modalities of biomedical science communication, such as biomedical science promotion, are of use. Our research showed that developing an understandable and manageable biomedical science communication process starts with asking questions, thinking and re-thinking. Start from the context of the problem and then take a look at the different possibilities. Therefore, every science communication professional or communication professional should work from a broad scope of ideas. This broad scope should be delivered in a manageable and understandable way to the biomedical science communication practice in particular or to the practice of science communication in general.

Again we have many more possibilities which could be used to develop an understandable and manageable biomedical science communication process. The model, the instrument and knowledge on the position of biomedical science communication show the theoretical and practical possibilities needed for analysing and implementing an understandable and manageable biomedical science communication process.

### 7.3 Research constraints

As we learned from our library search for systematic literature research and interviews with researchers in the fields of sociology, linguistics and philosophy, systematic literature research is not widespread in social research. The most important result of our systematic literature research is that the search and the evaluation as well as the use of the literature with the strongest convincing power are transparent. However, we could have chosen more and different libraries or library systems which might have changed the outcome. From the literature we read in this explorative descriptive study we have selected the most important information according to our criteria for the convincing power of literature as described in chapter 2 of this thesis. This of course could be different in the hands of another evaluator, who might have selected and read the consolidated and the unconsolidated literature. But again, in the end the process has been made transparent and the selected literature did strongly stimulate the articulation of questions and problems which otherwise could not have been asked.

Despite the fact that ideas and strategies from health communication, medical psychology and commercial communication are powerful components in the field of biomedical science communication, one must always be careful. There are differences in emotional distance (health communication), differences between the individual and the public (medical psychology) and differences in ethical constraints (commercial communication). These differences became apparent during operation but there might be constraints that are less obvious and that might influence the effect of using concepts, theories, models and constructs as well. Therefore one needs other communication domains for comparison. Moreover reflection on the use of theories and strategies by biomedical science communication professionals should be enhanced to get the necessary feedback from practical experiences and views.

One of the future questions to be answered is the cultural difference between countries in emphasising different aspects of the biomedical science communication process. This is certainly apparent when it comes to ethical constraints, and to notions and attitudes of target audiences on the issue of predictive DNA testing. Is the questionnaire a universal questionnaire? Which are the non-culturally bound aspects of communication on biomedical issues? Is emotional distance - mentioned in this research as a difference between health communication and biomedical communication - also an issue in India? Are other aspects of life as important as the aspects of health and biomedical issues? We have now found the vocabulary to ask more precise questions.

The test regarding the questionnaire is a qualitative study from which we wanted to learn whether the model we developed is one that is recognisable for researchers and practitioners in the field of biomedical science communication. Moreover, we wanted to know how large a gap exists between theory and practice. The questions on communication risk were most difficult to answer. When communication risk was more explicitly formulated the respondents might succeed in reflecting on the communication risk as well. This is essential in order to assess whether or not the development of a communication process should be continued. Therefore, researching the assessment of communication risks should be a focus of future research.

As previously stated, the instrument including the literature database could function as a platform for further development from which researchers and professionals could learn and begin asking questions. This would also improve the instrument and its use as it is a self-referential instrument. Every question raised by the instrument generates research and practical solutions, which in turn develop more questions. This is similar to the course of scientific research, but the platform might bring focus to the developments in theory and practice and keep both connected. In the next section questions for future research are described.

## 7.4 Future research

We have developed new angles for researching biomedical science communication to make it more understandable and manageable in practice and potentially more effective in the future. For the latter evaluation studies need to be carried out. All possibilities could be formulated more specifically but we should choose the main elements at this stage in the development of biomedical science communication. Future research on biomedical science communication needs to be more specific and focussed. Moreover, the national and international community of science communicators should develop a research agenda and programme in which the main issues of science communication are articulated in correspondence with biomedical science communication and science communication practice. From the conclusions on structure, process, outcome and context, future research should focus on:

## Structure

The question obtained from the most relevant and valid literature is mentioned first:

- o the construction of a message in its different components;
- o low threshold access to communication processes for a target audience, phasing and timing of the communication process;
- o the role of a research liaison officer.

These questions could be researched in an experimental setting, for example. In a message, a narrative component could be emphasised and tested in the case of biomedical science communication on predictive DNA diagnostics. A focus group of respondents would then be asked for their opinion on the most effective message. To start, the research should be qualitative rather than quantitative in order to develop a valid survey. The methodology of carrying out this kind of research could be obtained from studying commercial advertising.

## Process

The question obtained from the most relevant and valid literature is mentioned first:

- o further specific development of the many constructs and variables found in our comparative study, such as self-efficacy, knowledge locus of control and motivation and central and peripheral processing of information. In our opinion emphasis should be given to these main variables according to existing theories, models and concepts such as HBM, PMT and ELM. We pointed to the importance of these variables, but which variables attached to self-efficacy itself are specific to biomedical science communication in particular and to science communication in general? Moreover, the relation of these new variables should be placed in the context of the different biomedical science communication modalities. For example, self-efficacy could be part of a survey in which a target audience, not directly involved in predictive DNA testing, is asked about their ability and willingness to understand genetics at a certain level. Such questioning also takes the Eurobarometer research further, not only by asking what people know about DNA and predictive testing, but if they feel capable of becoming interested in this field of knowledge. This generates more insight into the motivation of the target audience and its state of possible empowerment. Moreover, we gain insight into the dynamics of the biomedical science communication process. Communicametrics could function as an 'enabling technology' to gain more insight into the different dynamic system levels. Other variables are: notions, expectations, the meaning of knowledge for an individual. Concerning the latter, a connection should be found with studies such as the psychology of knowledge and the basic notions of science and technology of the target audience;
- o from these constructs and variables biomedical science communication policy and strategy could be further developed. This is important from a practical view, since this is really in addition to the checklists mentioned in chapter 1. Aspects such as timing, framing and dynamics become more important depending on different contexts and target audiences. For example, empowerment as a variable is difficult to aim at directly for any target group, as we described in chapter 4. Therefore elements such as asking questions and strengthening motivation are needed. This means the secure planning of a biomedical science communication process for improving motivation leading to empowerment. With the research for this secure planning the assessment of the risk of miscommunication should also be taken into account;
- o as has been articulated many times before: evaluation studies are strongly needed. By articulating more constructs and variables and the strategic insights mentioned above, criteria for success could be more easily developed. Evaluation should be carried out at the level of structure, process and outcome.

By testing the different policies and strategies in a fixed context ('communication laboratory') both an effective strategy and policy development could be obtained, and different constructs and variables could be tested. Then the theoretical framework that makes biomedical science communication on predictive DNA diagnostics understandable and manageable might become a model for effective biomedical science communication.

The fixed context is to be understood as a real-time context from practice and not an artificial one. Of main importance is the idea that the fixed context is equal to the different policies and strategies tested. This is more like the 'clinical trial' of a newly developed communication process. Such a trial can be developed from the available theory. Moreover, by using academic corporate offices as a testing ground, strategy, policy, constructs and variables could be tested in real time. Moreover, this kind of communication could strengthen the reputation of the university by exploring frontiers, not only in their research but in their communication about research as well.

### *Outcome*

The main conclusion on outcome is that there are many possible outcomes, all of which are needed. These outcomes may fit non-context bound outcomes such as knowing a great deal about science, insight into the process of science, and knowledge of the impact of science as mentioned in chapter 1. Research on outcome should therefore be to develop criteria belonging to these different outcomes. What exactly does awareness mean to an individual? What are the expectations of a lay audience about predictive DNA diagnostics? Which outcomes belong to use of knowledge by an individual and which outcomes belong to growth and notions of an individual's knowledge? These insights are also needed in order to develop a proper evaluation instrument.

### *Context*

One of the main questions for future research on biomedical science communication and context is the way the many constructs and variables of context could be of use to the development of an effective biomedical science communication process in practice. Therefore, comparison between similar communication processes in different contexts is needed. Such a comparative study could reveal the variables that are apparent and important in each different context, which could be the main variables or 'meta-variables' of context within a communication process. These variables should be taken care of in all communication processes. Emotional distance might be such a meta-variable. For biomedical science communication processes, emotional distance is of main importance, as we have pointed out in our research.

In addition to this research agenda for further research on structure, process, outcome and context we can also contribute to:

- o diminishing the gap between theory and practice: instrument development. The instrument as we developed it in chapter 6 should be further investigated by using the research described above. Moreover, one of the principle items for evaluation is the interaction between the theoretical field and the practical field of biomedical science communication. As stated, the instrument is self-referential. This research is useful for practice and theory and can certainly help biomedical professionals to articulate their challenges and considerations in accordance with theoretical developments. Therefore, the questionnaire has been digitised and part of our future research will focus on the improvement of this instrument. Research could focus on: 1) the development of instruments for effective biomedical science communication. In the future this instrument will be digitalised and become a biomedical science communication process assessment (BSCPA tool); 2) quality instruments for reducing the risk of miscommunication; 3) the development of design heuristics of biomedical science communication. Instruments and theories could form a solid basis in the development of such heuristics (Slater, 1999). The development of an instrument, a design methodology or a heuristic contributes to the professionalisation of biomedical science communication practice, because insight into (for example) the risk of miscommunication supports both the management of expectations and the management of a budget;
- o position of biomedical science communication. Further research on the variables shows that the position of biomedical science communication is becoming more differentiated. The different modalities might become scientific and professional disciplines in themselves. This should be in line with the developments that have occurred in so many scientific disciplines and their practices.

- o biomedical science communication and its role in society. Interaction with researchers in the field of social studies of science should be sought. Not only in order to incorporate results from their field of research, but also because, in our opinion, interaction with biomedical science communication can contribute thinking and research on societal issues such as medicalisation and genetic essentialism. In section 7.5 we conclude with this remark.

### *Multidisciplinary research*

As shown in this thesis the incorporation of different scientific domains is useful. In our opinion, the natural sciences as well as mathematics could also be a source of inspiration. Mathematics, for example, can support logical thinking and experimental design. It has already done so for social science in general. In this thesis we learned from chapter 4 that communicametrics, for example, can be a useful grid for thinking and re-thinking variables and their relationships with each other in a dynamic environment. Also, the assessment of risk and management of risk could be supported by knowledge from different fields, such as physics, which for example describes uncertainty profoundly. In the future, when another domain is compared to biomedical science communication, five questions could be asked in order to select a domain:

1. What is to be expected from the domain in practice and theory?
2. What are the differences between the domains?
3. What are the differences on a theoretical level?
4. What are the differences in function?
5. What moral and ethical constraints can be expected?

If there is no match at one of more of these points, or there are no ethical and moral differences to define, one must be careful in taking such a domain into account.

### *Communication science*

In chapter 1 we described categories of communication theories, communication models (in chapter 3 we added behavioural models, intervention models and planning models), communication systems and effectiveness. As a result of our findings as well as the insights into the complexity of biomedical science communication we may prioritise these categories when incorporating them into the domain of biomedical science communication. In this developing phase of biomedical science communication we should try to find connections with:

- o theories of persuasion, such as social judgement theory, the elaboration likelihood model and the cognitive dissonance theory. Theories of leadership and theories of mediated communication might need a more profound theoretical foundation than biomedical science communication has at this point in time;
- o social theories, communication theories, theories of meaning, socio-psychological theories and sociological effect theories. These are fields of theoretical development that are close to the variables we found in our study. Media studies and text production theories are – in our opinion – of lesser importance since there is no established profound theoretical foundation as a reference point for biomedical science communication. One could start his research from the domain of media studies, but it might be a better idea to first put effort into the more fundamental questions of biomedical science communication. This comes close to the need of an internationally arranged research agenda;
- o structural model and the dynamic model. This could be of primary importance while we search for the main variables of a dynamic, multipurpose and multileveled system (as described above). The functional model and the operational model are however of secondary importance, since the dynamics of process variables are more complex than descriptions of the functions of process variables. The operational model also needs insight into structure and the dynamics of the communication process;

- o furthermore, we may focus on mass communication processes in which different communication processes can be compared within a single culture. For example, if we use communication between groups, the differences in subcultural variables will be added to the already existing complexity of the communication process and hinder the development of biomedical science communication in this phase of development.

Communication science as such is not a fundamentally scientific discipline. It only becomes meaningful in a certain context. This context asks for the involvement of different fundamental disciplines, such as sociology, psychology and linguistics ('the classics') but in specific contexts information on, for example, genetics and its impact is also needed (insights from social studies of science). Variables of these more fundamental sciences are used in strategy and determining policy for biomedical science communication processes. Together with this the development of instruments and heuristics which bridge the gap between theory and practice is needed.

## 7.5 Predictive DNA diagnostics

When we understand from communication perspectives the dynamics and systems levels of the process of the impact of biomedical research on predictive DNA diagnostics on society, we may contribute to the sociological research on medicalisation and genetic essentialism as well. Constructs and variables relevant to communication may provide a more practical perspective on basic public notions concerning science and technology development. For example, the use of issue-irrelevant information obtained from commercial advertising and variables such as brand and product belief make clear which elements of predictive DNA testing are of importance for a target audience and thus play a role in social processes and developments such as genetic essentialism and medicalisation. Insight into biomedical science communication could help in drawing the line between science and society as sharply and clearly as possible and help in articulating questions from a social science perspective.

What do the theoretical framework and questionnaire developed in our research contribute to the societal domain of predictive DNA testing? First of all, on a functional level the framework and instrument make the use and the implications (personal and societal) of these tests accessible and more manageable from a communication perspective. On the conceptual level, the framework and instrument show important questions, challenges and problems of new medical techniques in relation to a target audience, and therefore making it more understandable from a communication perspective. How do lay notions change due to effective biomedical science communication? What is the best question to ask? For example, basic notions and cultural themes, but also knowledge of socio-psychological variables such as locus of control, self-efficacy, empowerment, emotional distance, and issue irrelevant information show the ways in which developments in predictive DNA diagnostics in the public domain interact with society and individual lives.

From the theoretical framework and instrument developed in this thesis the biomedical science communication professional can contribute to research in the field of social studies of science. Also, the questions raised by Kerr in chapter 1 should be mirrored with practices using biomedical science communication. In chapter 1 we quote Kerr: 'Instead we should focus upon the ways in which people and things create social order through their interactions with others'. Part of this creation of social order is fuelled by biomedical science communication in a more or less structured way. Which communication process variables provide trust and reliability? Are these variables also variables that are studied in social studies of science? Science communication may therefore function as a window into varying points of view on the more fundamental social studies of science.

More practically, databases on clinical genetics such as DISCERN and ACCE have been developed, based mainly on what people want to know on the subject of predictive testing. These models do not generate insight into how the

communication process could be designed with regard to timing and phasing. Therefore, developments in DISCERN and ACCE and biomedical science communication are important for the development of a communication process involving a lay audience. Therefore, researchers of DISCERN, ACCE and biomedical science communication should learn from each other. Different practices and theoretical fields should be connected.

In closing, writing this thesis we described new insights into the dynamic process of biomedical science communication; we developed a theoretical framework making biomedical science communication understandable and manageable; we developed an instrument bridging the theory and practice of biomedical science communication; we made a plea for closer collaboration on science communication and the social studies of science; and we generated many more questions since the time we started in 2000, questions which form suggestions for future research. We deepened and widened theory and practice. As a science communication professional this process taught me to be more modest in my professional advice, knowing that much is still unknown and that there are many that questions could, and should be asked.

Beginning with the idea that developments in biomedical science in a knowledge-based society need an involved audience, this research hopefully contributes to an urgently needed professionalised practice of biomedical science communication in particular and science communication in general. It already has in my own practice, in which the attention paid to peripheral routes, tailor-made messages, understanding target audiences, thinking about the empowerment of a target audience (as in summer schools for science journalists) has developed. This direct application in practice is what gives me the drive to broaden, deepen and further professionalise this thrilling field of communication.

Learning from this research and its relevance to practice, I also feel that we must urgently start to focus our practical and theoretical work on science communication in general, since science communication is a strategic element in the interaction between science and society, involving many scientific fields and practices. Claiming this strategic place - and this is one of the important questions to ask in the near future - generates context, focus and status for the field of science communication and its development. If the theoretical framework and instrument described in this research provide the groundwork for more profound theoretical development, multidisciplinary corporation and the enhancement of professional thinking beyond the means of communication, the results of this research could be considered a triple axe: enhancing science communication in theory, practice and position. How lasting this enhancement will be depends on you and me as science communication researchers and/or professionals.