Chapter 1

Biomedical science communication on predictive DNA diagnostics: a case study and aim of research

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Preface

A significant problem for the practice of biomedical science communication in particular and science communication in general is the lack of a profound theoretical foundation with which to improve the effectiveness of the communication processes. Biomedical science communication and science communication are in an early stage of theoretical development. This chapter focuses on the development of the research questions posed by this thesis regarding the establishment of this theoretical foundation.

As the different sections on the history of science communication, communication science, perspectives on science communication, and public notions of science and trust and credibility demonstrate, it is clear that there is not an easy method for developing such a profound theoretical foundation for biomedical science communication. Therefore, in this thesis we compare different domains of communication and communication science in order to gain insight into the available theoretical possibilities.

This introductory chapter will also make it clear that processes of communication cannot be considered outside of their social and cultural context. We have chosen the recent developments and the relevant contextual aspects of predictive DNA diagnostics as the central case for this thesis, as it is a major development in medical science in which society is directly involved. At the end of this chapter the research problem, research question and research goals will be postulated.

1.1 Introduction: biomedical science communication and the need for public information

We are in the middle of a new era in medicine, one that is based on genetics. This significant step forward in medical science and technology is at once very personal and quite elusive. Genetic medicine raises the hopes of individuals, but thinking about DNA and its impact on health can seem like thinking about radioactive radiation: You cannot see it, you cannot feel it, but you can become ill because of it. And of course you cannot hide from your own DNA! For this reason, public emotions about genetic medicine vacillate between hope, enthusiasm, doubt and fear. How can the individual be supported in this space of deep emotions that are switched on by this specific development in science and technology? In our opinion, communicating with the public about genetic medicine is an important element in the answer to this question. But the way in which public communication on biomedical science should be carried out is not clear at this time. And the stakes of genetic based medicine are too high to be played with. It is from this sense of urgency that we begin.

Medical news

Medical topics are the most popular subjects in science communication (Miller and Kimmel, 2001; Willems, 2002). The majority of the science news in the media is related to medical issues (Willems, 2002; Kerr, 2004) and health, health aspects and disease have attracted a great deal of attention from the lay audience (Van Dijck, 2002). Eurobarometer public opinion surveys have shown that medical doctors are highly trusted by a lay audience (EU, 2005). Medical developments and subjects are sensitive topics for individuals and society alike and therefore do attract the interest of the lay audience (Meijman and Meulenberg, 2002). Obviously, the lay audience perceives science news and medical science news differently. The interaction between medical society and the lay audience provides the grounds for medical developments and concepts to be praised or fought against (Meijman, 2002). According to Huisman (2002), this is a rhetorical battleground, a place where meaning is constructed, negotiated and exchanged.
An example of the interest of the lay audience and the public's interaction with medical developments is the popularity of television medical dramas, for example series like ER and St Elsewhere (Van Dijck, 2002). These programmes are able to convey a message, though it isn't advice from a medical doctor.
This change in television programmes with medical themes occurred over time. On Dutch TV the focus has changed from the doctor and his expertise to the patient and his problem (Verhoeven, 2005). This is indicative of the development of the process of medical public communication. The medical story now is told from a personal perspective instead of a scientific perspective. Medical communication is not only communicated by facts but also as a personal story, in which meaning is constructed, negotiated and exchanged. As Baird (2002) described this development:

> *Given today´s short sound bites and media pieces, it is much easier to transmit the idea that ´genes cause illness´ than the idea that genetic makeup interacts over a lifetime with life circumstances and exposures to determine health.*

Biomedical science communication as a field of research and practice differs from science communication particularly because of the differences in interest in, and perception of, the medical subject by the lay audience. Beyond the public's interest in medical developments and trust in the medical profession, medical research sometimes has far-reaching effects for both society and individuals. Insight into effective communication serves as a solution to a societal problem in which the far-reaching effects of medical research are disconnected from individual development on a cognitive and emotional level. In order to gain this kind of insight, however, a profound theoretical foundation for effective biomedical science communication is needed.

As this introductory chapter makes clear, theoretical developments in biomedical science communication in particular and science communication in general fall short of supporting such a theoretical foundation. Therefore, in this thesis we have searched for theoretical developments in other, related fields, such as health communication, medical psychology and commercial advertising and applied these findings to a profound theoretical development of biomedical science communication.

Why biomedical science communication? Biomedical science communication is a form of public communication on developments in medical research and practice, most of which has a biomedical nature. A closely related field such as health communication (as we will analyse in chapter 3) is not necessarily attached to biomedical practice or research; instead, it aims directly at the personal level of aspects of health. This in turn differs from doctor-patient communication which is interpersonal communication on both biomedical issues and health. We describe biomedical science communication in relation to these domains as: public communication on developments in biomedical research that is aimed at a target group, at a non-personal level. These descriptions of health communication, doctor-patient communication and biomedical science communication give an indication of how much of communication depends on the distance the individual or the target group has to the medical subject and the medical information needed.

The public's biomedical information need

Insight into the public´s need for biomedical information is necessary for an effective biomedical science communication process (Meijman and Meulenberg, 2002). Moreover, it is important to know which level of knowledge is to be expected from the audience (Waarlo, 2002).

The need and level are variables in the attitude of the lay audience to biomedical science developments and the actors involved. Attitude is largely based on the associated psychological, socio-psychological, social and cultural variables. Miller and Kimmel (2001) use the term interest. For example, in the United States the strongest indicator for interest in medical subjects is having a friend or family member with a medical problem (Miller and Kimmel, 2001). Some variables influencing the interest they describe are shown in Figure 1.1.

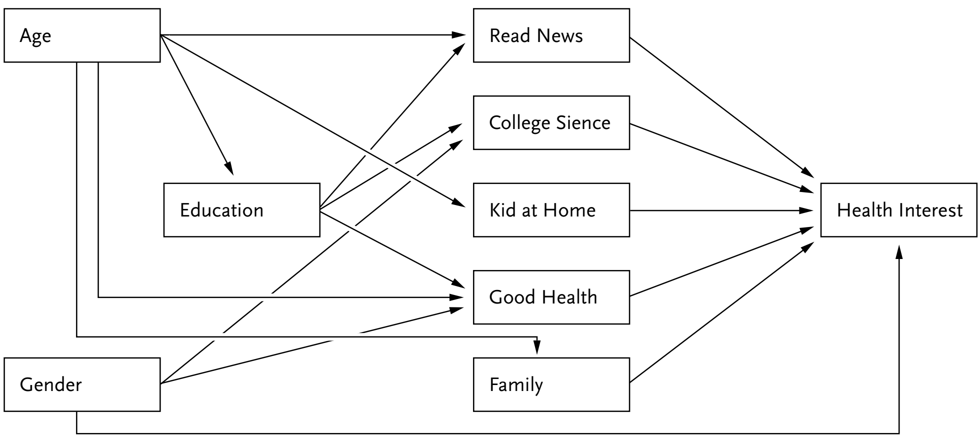

Fig. 1.1: Variables influencing public interest in health information (Miller and Kimmel, 2001)

From this diagram one can see that interest in health (both the need for it and the level of interest) is mainly associated with contextual variables like having kids at home, having good health, and general family health knowledge. As Miller and Kimmel found, health information as such does not automatically lead to interest in health issues. Miller and Kimmel's book, Biomedical Communications, is a thorough study of the information needs of different groups of Americans as well as their socio-economic status (SES) and other socio-cultural variables. Miller and Kimmel combined a variety of surveys to determine the variables of biomedical communication with an experimental basis. They conclude that:

1. the substantial differences in the level of biomedical understanding between the most and the least educated Americans indicate that it is necessary for communicators to send multiple messages with different levels of sophistication to different segments of the public;
2. long-term change is driven primarily by formal schooling, including the study of science and mathematics;
3. this suggests that some growth in understanding biomedical concepts and processes can and does occur during the adult years. For most Americans, however, the process of informal adult education is slow and requires a long-term communication commitment.

Important elements of their conclusions are the need for multiple-level messages to communicate different levels of information and the relationship between formal schooling and biomedical science communication. As we have already seen, the need for biomedical science communication is not just about facts; it is multileveled in terms of the target audience, the nature of the message, and the level of information provided, and it interrelates with doctor/patient communication and health communication. Miller and Pardo (2003) distinguish between differing publics: there is the attentive public; the interested public and the residual public. The attentive public includes citizens with a high level of interest in a given issue and a sense of being well-informed about that issue. For each different public the variables discussed are emphasized differently.

Based on their research, Miller and Kimmel developed a strategy for communicating to the public, which considers the scope, level, intermediaries and goals of the process (see Fig. 1.2).

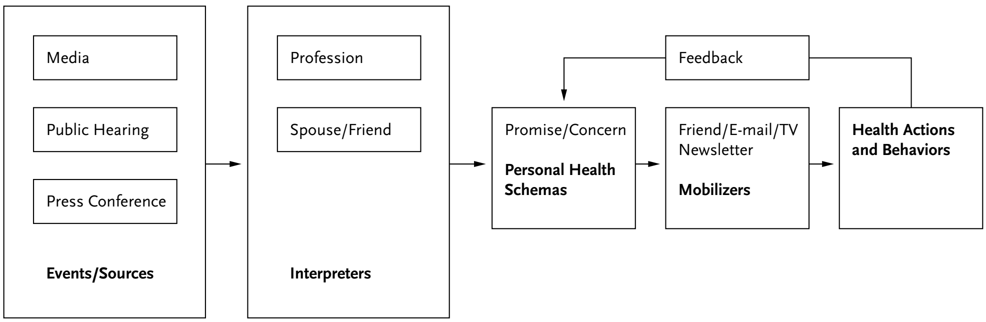

Fig. 1.2: A general model of biomedical communication to consumers (modified from Miller and Kimmel, 2001). This general model provides several examples of the movement of biomedical news and information from its point of origin inside the biomedical leadership community to the wider arena of an attentive public and other interested citizens. In this model the interpreters and the mobilizers are most important, as well as the personal schemas of the individual. The concept of a schema is most helpful in thinking about biomedical communication for health purposes and about the retention and organization of health-related information by citizens attentive to biomedical issues. These individual schemas individual might change attitudes and the willingness to action, due to the so-called mobilizers.

According to Miller and Kimmel, the aim of biomedical communication is to promote an awareness of health information and to promote good health practices. The aim of biomedical science communication - the subject of this thesis - is to provide insight into developments in biomedical science at different levels, achieving different aims for different target groups. Within this process, variables such as media influence and spouse/ friends play a role, as discussed above.

The next question is how all the findings of Miller and Kimmel can be meaningfully and manageably be put into practice. Miller and Kimmel propose the following checklist. In their words, one useful approach is to frame these implications in the form of a set of questions that might serve as checkpoints or reminders for biomedical communicators:

1 what information do you want to communicate and what actions (if any) do you want the recipient to take?;
2 who do you want to receive this message?;
3 what media or sources are likely to transmit the message to the target audience?;
4 what is the likelihood that the targeted recipients will hear, read, or view the message?;
5 what is the likelihood that the targeted recipients of the message will accept (believe) the message and incorporate it into their personal health schema?;
6 what groups or intermediaries might improve the likelihood that a message is received and believed?;
7 what is the likelihood that the targeted recipients will take the desired actions?;
8 what groups or intermediaries might improve the likelihood that the target recipients will take the desired action?;
9 how will you know how many of the targeted audience heard the message, accepted or believed it, and took the desired action?

As a part of the answers to these questions they found:

1 attentiveness to biomedical research issues is strongly related to a general interest in political affairs and is not simply driven by personal or family health concerns;
2 the attentive public for biotechnology policy issues is slightly younger, somewhat better educated, more likely to be biomedically literate, high-volume users of print media and electronically active [...]. They are likely to be frequent viewers of television news shows and of specialized science television shows such as Nova[1];
3 citizens – and especially those attentive to the issue – may feel more comfortable with information from major institutions and news sources about an established topic such as heart disease than with information about an emerging area such as biotechnology or ´genetic engineering.´

Important elements of the checklist and the answers are the strong influence of context, such as political developments and their effect on notions of trust and credibility and the belief or disbelief in new developments such as genetic engineering. The number of pathways for the distribution of this information is large. The flow of information today is a complex, multi-step process, involving various media, and it is likely that the complexity of this process will increase in the decades ahead (Miller and Kimmel, 2001).
Now that we know in what way information needs are divided and structured by processes, we also need to understand how to meet the public's information needs. What are the driving theories, concepts and/or models of the processes described? Except on an analytical descriptive level Miller and Kimmel do not develop a theoretical perspective which clarifies how all this is driven. A theoretical foundation of biomedical science communication still needs to be developed. Only knowledge of the theoretical foundation forms the sustainable basis

[1] An American television programme.

for the development of effective biomedical science communication. When one knows which variables of the process of biomedical science communication must be emphasized and interact, one may effectively steer an effective process. This is not only of theoretical importance - it is needed in practice as well. Next to the social importance of effective biomedical science communication, it has also become a strategic instrument in reaching organizational aims (Van Woerkum, 1999). There is an urgent need to be effective and to understand the drivers of this effectiveness. These are the basis of our research.

If biomedical science communication is lacking a theoretical foundation, what is the current state of science communication in general? Are theoretical developments in science communication sufficient to describe a theoretical foundation for biomedical science communication? Does the history of science communication provide insights into theoretical developments? Does communication science generate any clues to theoretical background? Are an understanding of public communication and accurate perceptions of the public helpful? Are insights into the social construction of medical science helpful?

We will begin with a brief history of science communication. We have done so because, from the viewpoint of this study, the domain of biomedical science communication is more closely related to science communication than to health communication.

1.2 A brief history of science communication

Science communication began with scientists debating amongst themselves in their own scientific language, most often Latin. The earliest scientists, including Bacon, Galileo, Descartes and Newton, communicated with the lay audience (Dalderup, 2000). Galileo and his dispute with the Roman Catholic Church is one of the great examples of a debate on science.

Before 1700, science communication was largely top-down. In the centuries afterwards, modern science communication developed, with discussions amongst the lay public on science, and with new media, like novels and theatre, entering the domain of science communication (Meijman et al., 2007). At a theoretical level, rather specific public roles can be identified over the course of history, but one must keep in mind that a mixture of roles is the rule. Felt (2003) defined four different roles in historical development.

In the first, the public are naive spectators meant to be fascinated, amused and impressed by science rather than enlightened. Science is presented as unique, magical, powerful and promising. The important part is the message, the image being conveyed, rather than the scientific or technological information that is imparted. The public were clearly perceived as consumers, and the popularization of science became a good for mass consumption. The second role of the public is as supporters of science. Either science has been ´sold´ as a general cultural good - a packaging that has proved to be increasingly suspect - or its practical applicability has been underlined. Once convinced of the importance of scientific knowledge, the public was supposed to be an ally of the scientists, arguing for more general funding or even exerting direct pressure for investment in particular scientific domains. An example of this in the medical domain is the growth of self-help movements, which, in turn, try to influence research in their particular areas. The public's third role is as witnesses. The public was used to testify in favour of experimental results and thus to assure the credibility and the authority of the scientist. The final role of the public is as a participant in doing experiments, a role performed in some disciplines (with great variation between nations) until the end of the 19th century. Since then, power has been entirely on the side of the scientific establishment. With the beginnings of modern empirical science, the attention of the lay audience expanded as well (Van den Broecke, 1993). The industrial revolution caused the feeling of immediate progress to grow rapidly. According to Dalderup (2000), in the 19th century (the age of science) mass media and museums gained importance as intermediaries between the audience and scientists. After World War II, a combination of rapid industrialization and declining environmental conditions brought

a call for more deliberation about the role of science and technology. Science communication needed more attention. During the first years after World War II, the central idea of science communication was that what is good for science is good for society. Although science communication did not yet exist as a discipline, there were already books on popular science, as well as popular science magazines. The growth of science communication in the years following World War II was in line with changes in governmental communication as well (Wiedenhof, 2000).
From 1960 onwards most Western societies have emphasized that citizens have a 'right to know'. This right to know extends to science and technology (Esmeijer, 1999). Publications like Rachel Carson's *Silent Spring* (1962) made many citizens aware of the dark side of science and technology. As Felt (2003) writes:

> *Blind trust in science vanished as science grew and negative impacts appeared. Simultaneously, information and public forums of exchange on science and technology have come to play a new and rather different role.*

The popularization of science must also be discussed in terms of power, political usefulness, and accountability. Awareness of these factors became the driving force of science communication. As Van den Broecke (1993) pointed out, one can question whether all science and technology developments are positive for all citizens and their environment. At the same time that there was euphoria about science and technology, citizens became more critical. Alarmed by Rachel Carson and by The Club of Rome[2], the lay audience became increasingly reluctant to welcome new technology. At the present time, there is more social support for genetics and genomics in medicine than there is for genomics in the food industry (Eurobarometer, 2005).
During the 1950s, academia's first concern became the social basis of research (Dalderup, 2000). In 1957, the Bender commission was formed to advise the Dutch government, focusing on trust in science and technology. The first science information officers were appointed at Dutch universities at the end of the 1950s. Wiedenhof (2000) states that from then on science communication was institutionalized in Dutch society. Dalderup (2000) writes:

> *From then on what is good for science is good for society is not valid anymore. It is better is to say that science is too important to leave it to the scientists.*

Together with the developments described above, science journalism in the Netherlands really got going at the beginning of the sixties, and was given great impetus in 1969, when the first man landed on the moon.

In 1974, the Dutch Minister for Education, Culture and Science founded a department of science communication (Esmeijer, 1999). In his white paper on science policy, Minister Trip stated that the needs of society must be reflected in science programmes:

> *Most science developments cannot be seen. There is a need to make communication with society stronger. This will help science itself, society, education and our relations with foreign countries.*

Trip's white paper focused on the grounding of science policy and science communication. In his view, the most important issues included financial support for science, the complexity of science when it is applied in society, and the need for democracy in society, government and science.

[2] The Club of Rome was a group of individuals who, in 1970, invited MIT researchers on system dynamics to research trends and developments of different threats to societies on earth. The MIT research was aimed at gaining insight into the physical limits to population growth and material use on our planet. The Limits to Growth. A report for the Club of Rome Project on the Predicament of Mankind, by Dennis L. Meadows et al., was published in 1972.

Not until the 1970s did people begin to systematically question the prevailing views and begin to deconstruct the process of knowledge dissemination. The rigid demarcation between 'genuine' and popular knowledge turned out to be problematic, for non-experts appeared to have their own models and representations, and these conceptions could not simply be ignored or called simplistic. The old dichotomy between scientific texts and popularized accounts gave way to a continuum of different kinds of texts. Popularization became increasingly understood as the negotiation of meaning (Felt, 2003).

All of these factors contributed to the first science communication initiatives in the Netherlands. Over the years, different organizations have been established: the Foundation for Bioscience and Society (Stichting Biowetenschappen en Maatschappij, 1969), the Netherlands Foundation for Public Communication on Science and Technology (Stichting voor Publieksvoorlichting over Wetenschap en Techniek, 1986), the Foundation for Science and Technology Weeks (Stichting Wetenschap en Techniekweek, 1985), the Rathenau Institute (Rathenau Instituut, 1994), the K.L. Poll Foundation for Education, Art and Science (K.L. Poll Stichting voor Onderwijs, Kunst en Wetenschap, 1983) and the Advisory Council for Science and Technology Policy (Adviesraad voor Wetenschaps- en Technologiebeleid, 1991).

Ten years after the publication of Trip's white paper, his successor Minister Deetman wrote another white paper, Integratie van Wetenschap en Technologie in de Samenleving (IWTS: Integration of Science and Technology in the Society). This white paper describes the influence of information, opinion and decision-making on developments in science and technology. In 1992, a government statement on science and technology communication was published, followed by Boeiend, Belangrijk en Betrouwbaar (Stimulating, Important and Trustworthy) in 2000. This latest note on science communication proposes a reorganization of the science communication process. In 2004, the WeTeN Foundation (formerly known as the Netherlands Foundation for Public Communication on Science and Technology, or PWT) lost its government funding.

The organization of the science communication process in the Netherlands is still under discussion. The Higher Education and Research Act, enacted in June 2006, made the valorization of science and science communication to the lay audience and other relevant target groups an official task of Dutch universities. Despite the fact that as of summer 2007 the law has still not been fully put into effect, at present science communication has become an official task of the universities, because science and technology have gained economic influence. According to the Lisbon Declaration (agreed upon by EU member states in 2002), Europe aims to be the world's strongest knowledge-based economy by 2010.

This means that there is an important role for science communication. According to Sclove (1995), science and technology are important in shaping today's democracy. In the last sentences of his book he writes:

> *This book has a simple message: it is possible to evolve societies in which people live in greater freedom, exert greater influence on their circumstances, and experience greater dignity, self-esteem, purpose, and well-being. The route to such a society must include struggles toward democratic institutions for evolving a more democratic technological order. Is it realistic to envision a democratic politics of technology? Isn't it unrealistic not to?*

Science and technology communication is essential to society, and as Trip stated, science is too important to leave to the scientists. One may conclude from this limited overview that the main change over time has been the institutionalization of science communication. Science communication goals have swung a long way from providing infotainment to an enthusiastic, naïve public, to providing understanding and science literacy to a public that is regarded as an important stakeholder in the process. Trust in scientists, and faith in their credibility is becoming increasingly important for the public. Meijman (2000) identifies the credibility and cogency of medical science as principle aspects of the process of biomedical science communication. Moreover, as described earlier and in the sections to follow, science communication is becoming an increasingly a strategic element in the policy and strategy of knowledge-based organizations and industry (Van

Woerkum, 1999; Wehrmann and Van der Sanden, 2007). There has even been a so-called paradigm shift, from the transmission of knowledge to the transaction of knowledge (Hanssen et al., 2003).
Despite these changes developments in science and technology are still often viewed by non-scientific audiences as a panacea or threat, with astonishment or disapproval. As Tuininga (2000) writes:

> *The industrialized world has science as religion, technology as their temple and efficiency as their dogma [...]. In earlier times the question addressed was ´can we make our wishes come true via technology?´ These days the question is ´are technological possibilities also desirable?'*

The target audience is not always aware of its own basic notions about science and technology. Knowledge of science and technology is just 'there' and is used for many purposes, from doctor-patient relationships to discussions in the pub. Despite all the worldwide communication efforts - as can be seen at the world congresses of the International Network on Public Communication of Science and Technology (PCST) - the distance between S&T and societal stakeholders is still substantial, despite the numerous communication activities.
According to Eurobarometer (2001), NWO/SCP (2000) and SWOKA[3] research (2000), the lay audience is neither familiar with scientific facts nor with the scientific method. In the United States, 50% of the population are inadequately informed on biomedical issues (Miller and Kimmel, 2001). According to Felt (2003), much of ´bringing science to the people´ has been thought of in terms of educating those who have been excluded, particularly members of the working class and women. Education has been perceived as a unique chance for social promotion. Raising the level of scientific literacy (i.e., knowing the facts and processes of science) becomes a question of social justice, and lack of scientific understanding is generally attributed to a lack of general education. The problem, however, is much more complicated since a high level of industrialization leads to low levels of interest in developments in science and technology (Durant et al., 2003; Bauer, 2006). This pattern suggests that we should distinguish between two qualitatively different forms of low interest in science and technology: ´disinterest out of ignorance´ in industrial societies and ´disinterest out of familiarity´ in post-industrial societies. Science communication is not only about understanding or a lack of understanding; the social and cultural aspects of S&T development in general and medical developments in particular are also of importance. In a society with a high level of industrialization science and technology are increasingly taken for granted, like food and housing. Already we can see that there are various elements that play a role in biomedical science communication: public disinterest out of ignorance, disinterest out of familiarity, a target audience's need for differing levels of information, different communication processes in which information is given and meaning is negotiated, factors of trust and credibility. From history we have learned that there is much at stake and that the development of science and technology has many faces. History however does not generate clues for a profound theoretical foundation to understand the complexity of biomedical science communication, except for the idea that interaction and strategic thinking are becoming more important. Which of the variables listed by Miller and Kimmel are appropriate at any given moment for interacting with a given audience? This is a question straight from the heart of communication research. As Laswell (1948, quoted in Rebel, 2000) once put it : ´Who says what to whom by which channel at what moment with what effect?´ Is answering Laswell´s question sufficient for creating solutions for science communication challenges? Probably not, because we can fill in all of the variables mentioned above and still have no answer to the question how, which we formulated earlier. In the next section we will take a look at science communication as a communication science discipline.

[3] SWOKA / Institute for strategic consumer research
NWO / Netherlands Organisation for Scientific Research
SCP / Social and Cultural Planning Office of the Netherlands

1.3 Science communication, communication science?

Despite its importance science communication as an academic field is still in its descriptive phase. A glance at the subject indexes of Public Understanding of Science and Science Communication as well as at the subjects of the PCST-9 (Public Communication of Science and Technology) conference in Seoul, South Korea in 2006, shows everything from media analysis to political involvement, to best practices of science communication in different cultures. A look at the article indexes (2005) of two of the largest international journals of science communication, Public Understanding of Science and Science Communication, reveals the present kaleidoscopic nature of science communication theory. It ranges from dialogue to the use of metaphors in text, to media analysis, public analysis, and gender differences. Sometimes there are effect studies, such as Michael D. Cobb´s 'Framing effects on public opinion about nanotechnology' in Science Communication and 'Public attitudes toward emerging technologies: Examining the interactive effects of cognitions and affect on public attitudes toward technology' by Lee et al. in Science Communication. Public Understanding of Science has two articles that are highly relevant to the topic of this thesis: Bates' 'Public culture and public understanding of genetics: a focus group study' and 'The effects of a genetic information leaflet on public attitudes towards genetic testing' by Sanderson et al. These articles and the kaleidoscopic character of the field - which is also to be seen in the few textbooks published in this domain - reveal both the scope and the complexity as well as the state of development of science communication. Which of the purposes and levels are the most important to investigate and support with a profound theoretical foundation? There have been a few attempts to develop a theoretical overview of this field or to create a utilitarian, more strategic point of view. Burns et al. (2003), for example, generated an overview of the different options, writing about the different aims and effects of science communication and identifying the different strategies needed to achieve an effect. The aims they describe are: public awareness of science (PAS), public understanding of science (PUS), scientific literacy, and scientific culture. Two more aims of science communication are described by Van der Auweraert (2003): public engagement of science (PES) and public participation in science (PPS). These aims fit the different roles of the target groups described in section 1.2: naive spectators (PAS, PUS), supporters (PES, PAS) of science, witnesses and participants in science (PPS, PUS).

Burns et al. also identify the following effects: awareness, enjoyment, interest, opinions, and understanding. They use the metaphor of climbing different mountains: i.e. the literacy mountain and the understanding mountain. From the perspective of science literacy, which consists of three components: 1) a vocabulary of scientific terms and concepts; 2) insight into the process of science; and 3) knowledge of the impact of science and technology on the individual and society (Miller, 1992; Irwin and Wynne, 1996; Miller and Kimmel, 2001). Gregory and Miller (1998) describe science literacy as 1) knowing a lot about science, 2) knowing how science works, and 3) knowing how science really works. Gregory and Miller emphasize that most of the scientific knowledge the public needs, and most of what the media present, is new science, science-in-the-making. This kind of science reporting strains everyone involved in the process of public understanding of science. When scientists themselves are struggling to understand science, journalists and the public face extra challenges in understanding the scientists and the science. In science communication, understanding of science is not only about the facts of science; the process of science could also be of interest to a target group (Van der Sanden, 2000). To understand the community's attitudes toward science, it is necessary to distinguish between ´knowledge´ of science and ´affect´ or mental position towards science. Herein lies the dichotomy between the public understanding of science (PUS) and the public awareness of science (PAS) (Stockelmayer et al., 2001). For example, messages in the media could be interpreted on three levels (Norris et al., 2003): the certainty and uncertainty expressed by scientists who are quoted in the media, the scientific status of the article and the meaning of the remarks quoted by different scientists.

Ogawa (1998, in Aikenhead, 2001) describes three orientations the public may have towards science. First, does the individual understand science (science literacy versus science illiteracy)? The second orientation is more emotional: does the individual support science (a pro-science versus anti-science position)? Ogawa´s third orientation is an ideological belief that scientific knowledge is the only valid knowledge to use in any context. This belief, called ´scientism´, prefers scientific knowledge above all other ways of knowing. This generates six categories of people:

1 science-literate, pro-science, pro-scientism: science believers;
2 science-literate, pro-science, anti-scientism: science contextualists;
3 science-literate, anti-science, anti-scientism: authentic anti-scientists;
4 science illiterate, pro-science, pro-scientism: science fanatics;
5 science illiterate, pro-science, anti-scientism: science vigilantes;
6 science illiterate, anti-science, pro-scientism: neo anti-scientists.

The four aims (PAS, PES, PUS and PPS) can be combined with the effects of science communication (awareness, enjoyment, interest, opinions, and understanding) on different levels of interpretation (the certainty and uncertainty about quotes from scientists in the media, the scientific status of the article and the meaning of the quotes by different scientists) regarding different audiences, as just described. This generates many possibilities for developing a science communication process. Moreover, the science communication aims, effects and levels could change over time. Once started, the variables described in the process will change and the effect of the process could shift from awareness to opinion, which probably requires a different strategy. Does all the above provide enough theoretical insight to develop such a strategy? We again can fill in Laswell´s summary of the communication process, but what are the driving theories behind those aims and effects? If the history of science communication and concepts of science communication do not generate grounds for a theoretical foundation, does communication science do so? In the next section we describe the relevant developments in communication science. This overview gives an idea of the current state of affairs with regard to the overall concepts, theories, models, constructs and variables of communication science in light of science communication.

1.4 Communication science

Communication is a so-called container item. The ease with which we use the word 'communication' does not reflect the complexity which is behind every communication process. For example, one can investigate the effectiveness of a communication process on different levels: 1) What type of reaction is desired from the target audience? 2) Within what time frame do reactions occur? and 3) Does the communication have an effect on society or at an individual level? At which level should the communication effect be measured? (Stappers, 1983). Dainton and Zelley (2005) write:

> *Communication is viewed as simply an activity among many others, such as planning, controlling, and managing (Deetz, 1994). It is what we do in organizations. Communication scholars, on the other hand, define communication as the process by which people interactively create, sustain and manage meaning (Conrad and Poole, 1998). As such, communication both reflects the world and simultaneously helps to create it.*

Nillesen (1998) describes communication as a transmission, interaction and ritual. Furthermore, he makes a distinction between flow, persuasion and information. Studying flow, one searches for social laws that make the communication process possible on a meta level. Nillesen distinguishes between flow influence and flow of information as two separate processes. Flow influence aims to change the respondent's behaviour, and flow of information is the next step. So communication can be seen as both a flow of information and as a flow of influence. Communication is both presentation and interpretation. The communicator creates, and the respondent interprets form and meaning, as Heuvelman and Van der Staak (1992) write. Communication is managing meaning. All this makes communication complex. How can one manage meaning when meaning has different dimensions for different individuals?

Science communication is also about managing meaning for different audiences on different levels and for different aims and effects. The question then is, which theories support the management of meaning? Which variables described in these theories and models[4] are in accordance with the variables of meaning in the field of science communication and could enhance the further development of the effectiveness of communication processes? What kind of theories are common within communication science?

There are numerous concepts, theories, models, constructs and variables to be found in communication science. Most of the time they are related to specific communication disciplines, like health communication, risk communication, governmental communication, corporate communication, etc. However, there are also categories of communication science theories to be distinguished.

According to Dainton and Zelley (2005), a theory is any systematic summary of the nature of the communication process. They describe the following different categories of theories:

1. theories of persuasion (such as social judgment theory, the elaboration likelihood model, cognitive dissonance theory);
2. theories of leadership;
3. theories of mediated communication (like agenda-setting theory, cultivation theory, social learning theory, and uses and gratification theory).

In more specific theories, Rebel (2000) distinguishes:

1. text production theories (which focus on sender and message);
2. sociological theories (which focus on sender and medium);
3. psychological theories (which focus on receiver and message);
4. communication theories (which focus on receiver and message);
5. media studies (which focus on the medium);
6. theories of meaning (which focus on the message);
7. socio-psychological theories and sociological effect theories (which focus on the effects).

All of the above theories seem to be relevant to the field of science communication. Now we can decide to apply these theories directly to the field of science communication. However, a theory, as defined by Dainton and Zelley, is a systematic summary of the nature of the communication process. So when we apply these theories directly to the field of science communication there is a chance that we will miss some specific contextual variables that are related and essential to science communication and biomedical science communication. As described in section 1.1 these contextual variables are of great importance to understanding and developing effective biomedical science communication processes. By first investigating which of the categories of theories of communication science are used in communication fields relating to biomedical science communication we develop a framework with which to interpret the categories, thereby reducing the risk of misinterpretation and misuse of communication theories. These categories of theories then become a frame of reference.

[4] *A theory* is a set of interrelated concepts, definitions and propositions that present a systematic view of events or situations by specifying relations among variables in order to explain and predict the events or situations (Kerlinger, 1986 quoted in Glanz et al., 2002) [...] In less advanced fields, theories specify the determinants governing the phenomena of interest (Glanz et al., 2002).
Models draw on a number of theories to help understand a specific problem in a particular setting or context. They are often informed by more than one theory as well as by empirical findings (Earp and Ennett, 1991, in Glanz et al., 2002).

The same problem of direct application in science communication also occurs at the level of communication models. The above theories lead to different models for communication on a psychological level, socio-psychological, and a sociological level. Within communication science, the following communication models can be distinguished (Fauconnier, 1992):

1. the structural model, which analyses the whole communication system. The emphasis is on ingredients such as message, sender and receiver;
2. the dynamic model, which describes the process itself, the evolution, the movement of sender, receiver and message;
3. the functional model, which considers the relation between different parts of the communication process (e.g., causality);
4. the operational model, which looks at strategy, programme, and evaluation (e.g., in public communication and commercial communication).

All these models could be of use in science communication. Again, this is not directly helpful in developing communication discipline. In looking in greater detail one sees that most communication theories and models are linked to different communication systems. One can see communication as a system in which the following systems can be distinguished (Fauconnier, 1992):

1. intrapersonal communication (within a person);
2. interpersonal communication (between persons);
3. communication between groups;
4. organizational communication;
5. categorical communication;
6. mass communication.

From the definition of biomedical science communication described in section 1.1 we know that intrapersonal and interpersonal communication systems will not be the main focus of biomedical science communication, at least as considered by this thesis. But the latter four systems are of use in the field of biomedical science communication. However, the differences between these systems have not yet been clearly described for biomedical science communication. Again, it is useful to study related fields in developing a framework with which to interpret these communication systems in the light of science communication in general or biomedical science communication in particular.

In the two sections below we focus on two important aspects of communication processes: effectiveness, and policy and strategy. The variables of the communication process mentioned in the previous sections are important to effectiveness. And as we have already shown, the variables are well described within theories and models. But these descriptions are rather static and because of the different audiences, and since aims and effects change over time, we need more insight into the dynamics of the process and its manageability. Communication policy and strategy may provide insights into these dynamics and their manageability.

Effectiveness

There are not many effect studies dealing with public communication (Edwards, 2004). A search of databases using the key term ´effectiveness´ produces few hits (see, for example, Tables 3.1 and 3.2 in chapter 3). The effectiveness of communication is not straightforward, and depends on contextual factors. One of the main purposes of this thesis is to investigate the variables that are relevant to the development of an effective biomedical science communication process. From theory, we have learned that there are five sorts of long-term effects (Fauconnier, 1992):

1. effects that depend on repeatedly communicating the message (for example, in commercial advertising). These are cumulative effects;
2. effects that are only seen or measured a long time after the communication process has ended. In mass communication, these effects are described as ´sleeper-effects´ (for example, messages from an unreliable source, which turns out to be reliable after all);
3. effects that lead to a structural change of behaviour. Normally this effect is seen after different stages, such as attention, interest, buying;
4. effects that lead to a sustained change of behaviour due to social networks and processes of legitimization. These include effects of socialization and cultivation, and changes of lifestyle.
5. mass media effects in relation to politics, industry, and the public.

These long-term effects are formulated in a broad sense on function and level of communication. This asymmetric list shows the range of action of communication.

De Boer et al. (1990) define the following variables of effectiveness: attention, understanding and judgment, change of knowledge, expectations, participation behaviour, and the sustainability of participation behaviour. Communication can only be effective when there is some kind of attention being paid. Rebel (2000) speaks of equality and common sense. If there is attention, the target audience might understand the message. The information therefore needs to fit the knowledge and experiences of the target audience (Seydel et al., 1984). Moreover, the message should be perceived as credible, expert, and reliable (McGuire, 1985). Participation and sustainable participative behaviour are important, as is the audience's socio-economic status (SES) (Miller and Kimmel, 2001).

These variables, and the others previously mentioned, do further develop the effects described by Burns et al. (awareness, enjoyment, interest, opinions and understanding) (2003). For example, a variable like ´expectations´ could be an element in awareness and enjoyment. These variables also make it clear that the ´classic´ sequence of knowledge, attitude, and behaviour is subject to rethinking.

These thoughts on effect and effectiveness are studied in a more comprehensive context with regard to biomedical science communication and its related fields. In the next section we focus on the dynamics of the discussed variables from the standpoint of communication policy and strategy.

Communication policy and strategy

Effective communication is based on a well-defined and properly implemented policy and strategy in which the different choices attached to the communication process are explicitly made. There is much literature on communication strategy in general and on the more strategic fields of communication, such as corporate communication and marketing communication. From this, we learn that making complexity manageable is one of the foremost issues. Integrated communication (Rebel, 2000) is one of the overall communication strategies, which combines different communication modalities to produce more effective communication processes and outcomes. Science communication, as a communication modality, has to cooperate with marketing communication, internal communication, and branding strategies, etc. As mentioned before, science communication has become an increasingly strategic element in communication by knowledge-based

organizations and industry (Van Woerkum, 1999). However, before integration is achieved one must know which variables are most essential to integration with the other modalities. Therefore, a theoretical foundation for science communication as well as for biomedical science communication is urgently needed.
The thinking about science communication strategy and policy is only just beginning. There is not much literature on this particular subject yet. Most literature on science communication has so far focused on contextual developments and on describing the factors of complexity. What one can see from science communication literature is the fact that policy and strategy have been consolidated to provide checklists for management. For example, Gregory and Miller (1998) propose the following checklist:

1 acknowledging the place of popularization;
2 being clear about motives;
3 respecting the audience;
4 negotiating new knowledge, understanding and attitudes;
5 establishing a basis for trust;
6 acknowledging the social science;
7 facilitating public participation.

This is not a very different checklist from Miller and Kimmel´s, mentioned in section 1.1. Miller and Kimmel´s checklist is more informational whereas Gregory and Miller´s is based more on action. But one still does not know what the driving variables behind the items on the checklist are and how to manage them. As one can see, this is far from science communication policy and strategy. This is about the possible conditions of an effective science communication process in which many variables play a role, like aims and effects, which are interrelated. From this early stage of development of biomedical science communication we may start managing all the variables and strategic possibilities in a simple way. One of the most useful and manageable classifications of communication strategies was devised by Van Ruler (1998): the communication intersection. In this classification forming, dialogue, persuasion and informing are the main strategic pathways. Of course, these pathways can change over time, so one could start with dialogue and end with persuasion. These are four strategies that represent four basic categories of strategic possibilities that form a grid for development. Again, by comparing fields related to biomedical science communication we are attempting to describe these four strategies in more detail for biomedical science communication.

In summary, we may conclude that many variables for the developments in biomedical science communication, science communication and communication science have already been described. It is clear that these variables and checklists by themselves do not form a theoretical foundation for biomedical science communication. How are these variables related in light of effectiveness and policy and strategy? Communication science theories, models and concepts may shed light on this conceptual problem. But after studying the communication science theories, concepts and models we have concluded that direct incorporation of the theories, models and concepts of communication science is not useful, due to the specific contexts of the communication processes. Therefore, as we have mentioned before, a comparison of biomedical science communication with closely related communication science domains seems to be more appropriate the effort to develop a relevant profound theoretical foundation for biomedical science communication.
Now that we have decided how to search for a relevant theoretical foundation we need to study the contextual variables of biomedical science communication since they are of importance, and use theory, concepts and models from the various communication domains as a comparison. In the next sections we will focus on the different perspectives on science communication. These perspectives describe the urgency of the need to communicate about science. We will then focus on the social construction of science, notions of science and technology development, notions of trust and credibility and the context for this research: predictive DNA testing.

1.5 Perspectives on science communication

Over two decades ago, Stappers et al (1983) warned about the purity of science communication as a public service. He wrote that science communication is a strategic communication modality for knowledge-based organizations such as universities (Van Woerkum, 1999; Willems, 1979). No longer purely aimed at increasing knowledge on an individual level, science communication also plays a role in sustaining the image and identity of the organization. Corporate policy goals like securing funding for research have become major communication targets for science communication (Kok and Van der Sanden, 2006; Wehrmann and Van der Sanden, 2007). In the context of a knowledge-based economy, knowledge is no longer a unique selling proposition, but has to be expressed in different ways to different target groups, on different subjects, at different times. Other modalities, such as business-to-business science communication, have become more and more important (Wehrmann and Van der Sanden, 2007).

The economic argument is quite recent in Dutch public science communication. From an agological perspective (Van der Ban, 1975), via a perspective that was based more on communication science (Stappers et al, 1983), public science communication has evolved and now has a more modern perspective, which fits the needs of science and society (Van Woerkum, 1999; Gregory and Miller, 2000; Stockelmayr, 2001) including the needs of the knowledge-based economy. Over the years, these perspectives, based on society and on the individual, have widened to include the economic perspective (Wiedenhof, 1993). Developments in science and society, and in communication science, have made communication directive. Interactivity (Hamelink et al., 2004; Meijman and Meulenberg, 2002a), non-directiveness, lay knowledge, and dialogue are key words associated with modern science communication. As Willems (2000) puts it, this has been a change from enlightenment to seduction. Instead of leading to ´science literacy´ communication now leads to ´science culture´ which contributes to empowerment and citizenship. These two terms form the basis for the arguments for science communication described here. 'Empowerment' means competence building: for example, learning to make informed decisions, both private and public, or learning to understand the essence of genetic revolution (Waarlo et al., 2002). 'Citizenship' has been described as an ´office´ from which an individual can derive rights and from which one can address the government and one's fellow citizens (Bovens, 1997). The ideal of informed decision making, with an emphasis on citizen participation and empowerment, is linked to a particular concept of citizenship (Van Gunsteren, 1992). This concept of citizenship emphasizes public interest and participation in public affairs and debate (Waarlo et al., 1997). This brings us to four significant arguments about science communication: the democratic argument, the social-cultural argument, the economic argument, and the lifelong learning argument (see Box 1.1).

Box 1.1:

Democratic argument (Haldane, 1939; Trip, 1974; Willems, 1976; Stappers et al, 1983; Royal Society, 1985; Nelkin, 1987; Durant, 1991; OC&W, 2000; Willems, 2000; Van den Bossche and De Greve, 2000; Stockelmayer et al., 2001): Every individual has the right to know about developments in science and technology. This is necessary in order to formulate one's own opinion and ideas, in order to make choices about new developments. Moreover, the individual has to be able to participate in public debate on science and technology developments. Some authors describe this democratic argument as a practical argument for science communication (Royal Society, 1985; Durant, 1991; Irwin and Wynne, 1996).

In addition to its positive aspects, this right to know has a negative side as well (Dekkers, 1980), associated with the difficulty in protecting the individual's right. Science generates more possibilities but also more responsibilities both for the individual and for society. This right to know also affects governmental expenditures on science (Willems, 1976; Nelkin, 1987). Moreover, in this way citizens become involved in societal decision making (Dalderup, 2000). In the specific case of communication on biomedical issues, Mol (2006) says the lay audience do not always want to look for answers themselves, and the logic of making choices is different from the logic of care. In health care the practice is pointed towards good care. Mol states that the choices made by a layperson may be in harmony with good health care, but they can be contradictory as well. The desire to make choices may erode the practice of good health care.

The social-cultural argument (Trip, 1974; Royal Society, 1985; Durant, 1991; Stappers, 1983; OC&W, 2000; Willems, 2000; Dalderup, 2000; Stockelmayer et al., 2001): Science is part of our culture, so everybody has the right to participate. Science is interwoven with society, both are influenced by socio- cultural factors and cause socio-cultural changes. Knowing about science makes the contemporary human environment more understandable. For example, it provides insight into the gap between science and humanities that was depicted by Snow in 1959 (Dalderup, 2000).

Economic argument (Trip, 1974; Stappers, 1983; Royal Society, 1985; OC&W, 2000; Willems, 2000; Dalderup, 2000; Stockelmayer et al., 2001): Science is essential to economic growth, so a societal basis for this driving force is necessary. It concerns not only money, but also a well-educated workforce. Communication is necessary to a knowledge-based economy, as declared by the European Union in 2002. For example, valorization as an element of science communication is becoming an increasingly common function of universities.

Lifelong learning argument (Stappers, 1983; Heuvel and Van der Staak, 1992; Willems, 2000): Knowing about the new developments in science is essential, and since this is a continuous process, science communication must also be continuous in character. This argument and the argument for infotainment (Willems, 1976: Esmeijer, 1999) relate to the fun of knowing about science. As Willems (2000) says, ´Scientific developments are a source of entertainment and give relief to life in monotonous modern society'.

Although all the arguments seem plausible, some critical remarks can also be made. Miller (1992) questions the argument that communication about science and technology is necessary for society. He asserts that it might amount to nothing more than glitter in a modern world. Moreover, it has been found that in the United States, for example, only 20 percent of the population are really interested in science (Miller, 1992). It is not known whether more interested people tend to make more informed decisions. The Eurobarometer research does not support this conclusion (Bauer, 2006). Stappers (1983), asks, Does everybody need to know about science? As he points out, not everyone needs to speak Portuguese fluently, either; he calls the notion that everybody needs to know about science the 'dogma of the benefit of communication'. Tichinor (1974) and Hanssen (1999) have discussed the knowledge paradox: people who have knowledge acquire more as a result of communication, whereas people who don't have knowledge don't benefit from the communication effort at all. All of this forms the context for biomedical science communication, a context that starts from the notions of science and technology from a public perspective.

1.6 Public notions of science, trust and credibility

People hear and read about science and construct their own personal scientific contexts. In Brave New World Aldous Huxley (1946) wrote about genetic developments, warning against an optimistic view of the future consequences of genetic developments. In the foreword to Brave New World Huxley writes:

> *The theme of Brave New World is not the advancement of science as such; it is the advancement of science as it affects human individuals. The triumphs of physics, chemistry, and engineering are tacitly taken for granted. The only scientific advances to be specifically described are those involving the application to human beings of the results of future research in biology, physiology and psychology.*

It is not that easy to affect the human mind. Notions, world views and cultural factors determine the most individuals' frame of mind. Therefore, to achieve a change, science and technology must be changed (Eckersley, 2001), at least in terms of outreach. According to Eckersley, while science must remain rigorous, it must also become less intellectually arrogant, more culturally integrated, and more politically influential. Science must become more tolerant of other forms of reality, other ways of seeing the world. It must become less remote from public culture, so that a steadier and readier exchange between the two is possible. But what is public culture regarding science and technology? What are these public forms of reality? What are the gates to cultural integration?
First of all, a distinction can be made between people with a holistic world view and those with a reductionistic world view. At a more basic level, a distinction can be made between conceptual and functional (utilitarian) thinking and between theoretical and practical approaches. Pott (2006) mentions some other dichotomies pertaining to the scientific point of view: Platonists/Sophists, universalists/contextualists, rationalists/constructivists and realists/relativists. These different world views are more obvious in science than they are on a societal or individual level. For example, in medical information search behaviour, these world views make a difference (Boot and Meijman, 2006).

Parales-Quenza (2004) formulates three basic cultural dichotomies in the case of genetically modified (GM) food: natural/artificial, tradition/change, health/disease. These primary components, Parales-Quenza writes, allow participants to associate with a subject about which they have little knowledge, though they do have opinions. The cultural dichotomies and basic notions described below are important to the development and design of the science communication process. Communication will certainly fail if the message is not tailored to the audience's specific basic notions and themes. A neo anti-scientist will probably not listen to a message aimed at a science believer. The practical differences between these approaches in biomedical science communication should be the subject of further research.
Smits (2002) describes four ways of coping with new trends in technology in general, which will be discussed later in this section. One can see that different attitudes require different science communication modalities and different communication goals. For a full explanation see Box 1.2.

Box 1.2:

Smits uses the metaphor of monsters to explain the different ways audiences can get involved in developments in science and technology. The order of the styles reflects the amount of fear of monsters, starting with the greatest amount of fear in Exorcism, and ending with fear being replaced by fascination in Embracement:
Exorcism, driving out monsters: in this dogmatic approach to science and technology, there is little room to change or adapt existing ideas. Developments in technology and science are experienced as threatening and must be shut out;

Adaptation, adapting monsters: in this approach, the audience is less apprehensive of science and technology than in the first case. Although it is not a part of their lives, the audience does not condemn it;
Assimilation, assimilating monsters: here, the boundaries between people and science and technology can be overcome. Smits points out that the boundaries here are more instrumental than fundamental, and there is no inherent resistance to the developments in science and technology;
Embracement, embracing monsters: Smit refers to this approach as romantic, because it so clearly differs from the struggle for clarity and control that is present in the first two styles, and partly in the third.

Durant et al. (2003) describe these attitudes towards science and technology in Eurobarometer terms: 'progress, panacea and future shock [...]. It captures the public's sense of pessimism versus optimism about science'. Greenhalgh et al. (2004) describe different attitudes towards risk which depend on various cognitive biases: 1) acceptable risk; 2) anchoring; 3) availability bias; 4) categorical safety and danger; 5) appeal of zero risk; 6) framing of information; 7) illusory correlation; 8) distinguishing between small probabilities; 9) personal versus impersonal risk; 10) preference for status quo; and 11) probability versus frequency. For a full explanation see Box 1.3 (Greenhalgh et al., 2004).

Box 1.3:

Acceptable risk: Some risks (such as lung cancer from smoking) are subjectively viewed as more acceptable than others (such as vaccine damage), even when the probabilities of occurrence are much higher. Hazards generally deemed acceptable are familiar, perceived as being under the individual's control, have immediate rather than delayed consequences, and are linked to perceived benefits.
Anchoring: In the absence of objective probabilities, people judge risk according to a reference point. This may be arbitrary – for example, the status quo or some perception of what is ´normal´.
Availability bias: Events that are easier to recall are judged as more likely to happen. Recall is influenced by regency, strong emotions, and anything that increases memorability (such as press coverage and personal experience).
Categorical safety and danger: People may perceive things as either ´good´ or ´bad´, irrespective of exposure or context. This may make them unreceptive to explanations that introduce complexity into a decision (such as balancing benefit and harm).
Appeal of zero risk: The elimination of risk is more attractive than reduction even if the relative reduction is of the same order of magnitude as the elimination.
Framing of information: A glass can be described as ´half empty´ or ´half full.´ The problem is the same, but it is framed differently. This can have a direct and powerful impact on decisions of both laypeople and professionals. Losses can loom larger than gains.
Illusory correlation: Prior beliefs and expectations about what correlates with what lead people to perceive correlations that the data do not present.
Distinguishing between small probabilities: We cannot meaningfully compare very small risks (for example, of different adverse effects), such as 1 in 20,000 and 1 in 200,000. Expressing harm as relative rather than absolute risk dramatically shifts the subjective benefit-harm balance, because the risk of harm seems greater.
Personal versus impersonal risk: Health professionals and patients may have different preferences, perhaps due to different knowledge about outcomes and inherent differences in making decisions about themselves or others. Those making judgements about others tend to be less risk averse than those making judgements about themselves.
Preference for status quo: Most people are reluctant to change current behaviours, such as taking a particular drug, even when the objective evidence of benefit changes. It may be due to an illusory correlation.
Probability versus frequency: Poor decision making is exacerbated by the use of absolute and relative probabilities. Judgment biases are less common when information is presented in terms of frequency.

Developments in science and technology and the notions and information needs of the public are at the basis of all science communication processes. The notions and information needs of the public are variable and often lack explicit representations. For example, Greenhalgh et al. (2004) write about drug regulatory decisions, which are to some extent socially constructed through active and ongoing negotiation between patients, practitioners, and policy makers. All parties should recognize that non-rational factors, as described above, are likely to have a major influence on their perceptions.
All these ways of coping with developments in science and technology can be addressed within the domain of science communication, but may require different approaches. Exorcism may need a certain type of dialogue with content that differs from the communication addressed to the other three ways of coping. According to Smits, in the case of developments in science and technology, it is more useful to ask what we want to be responsible for than to ask what we want to have. Cultural themes and (social) beliefs are affective. Beliefs are, therefore, more or less immune to factual information. To quote Parales-Quenza (2004) :

> *By emerging from [cultural] themes, core contents [of a social belief system] become affectively laden, which explains why some of them function as attitudes. This fact explains the primacy of affect in the conformation of shared beliefs, and the fact that preferences do not necessarily require information.*

When discussing and debating, it is therefore important to recognize other opinions and to negotiate from different points of view connected to cultural dichotomies, ways of coping and attitudes towards risk. According to Pott (2006), pluralism might form the starting point for such research. As Pott sees it, pluralism is the understanding that in science more than one theoretical reality can be developed in parallel. This may be useful to science communication, since notions of pluralism may make it possible for people to think about their own position with respect to the developments in science and technology. The process of biomedical science communication therefore can be contextualized using these notions and concepts of science and scientific thoughts. As we state in chapter 5, nothing in biomedical science communication makes sense, except in the light of context. Given this ´handicap´, trust and credibility are essential (Meijman, 2000).

Trust and credibility

As we have seen, one of the problems in science communication is the different perspectives on science held by different actors (Irwin and Wynne, 1996; Greenhalgh et al., 2004; Ogawa, 1998). According to Irwin and Wynne, it is not possible to generalize the meaning of science for different groups in society. Huizinga (1983) speaks about the changes which have occurred as public communication has moved from a *plantation model,* where a primitive lay audience gains knowledge by instruction and even repression; to a *technological change model,* where the target group plays a more central role, though the communication professional still knows best; to a *problem-solving model,* where the target audience and the communication professional try to solve the problem via mutual understanding. This can eventually lead to an audience which is in control of the process. Van Woerkum (1982) makes a distinction between 1) informative communication, aimed at increasing knowledge, 2) educative communication, aimed at helping the target audience make decisions, and 3) persuasive communication. According to Van Ruler (1993), the term 'public communication' has expanded, becoming more general, a synonym for communication. In her opinion, communication has two modalities: 1) a service argument (e.g., informative and educational communication); and 2) an instrumental argument (e.g., persuasive communication). According to science communication, the service argument especially serves the democratic argument and the socio-cultural argument.
Central to these processes are the individual freedom to make decisions, the interest of the target group, and the solution of explicit problems (Van Gent, 1985). Van Gent gives the following definition of the problem-solving model:

> *A systematic action to service a target audience with knowledge and insights so they can develop their own responsibility in making choices. Both sender and receiver are active in this network. The altruistic communicator services a willing respondent.*

So the meaning of science for a lay audience depends on how that audience uses scientific knowledge, or neglects it. Once we leave the so-called cognitive deficit model of public understanding of science, it becomes clear that there are a lot more possibilities and constraints in the communication of science in general (Gregory and Miller, 1998) and biomedical science in particular.
The cognitive deficit model only considers the differences in scientific knowledge between scientists and the lay audience - it is only about deficient cognitions. Yet, as we have seen, science is much more than just a matter of cognition. Despite this, science communication practice is still based on the deficit model:

> *Although almost two decades of work in the sociology of science and technology have undercut the theoretical and methodological foundations of the so-called deficit model, it is alive and well in the science communications industry and the policy communities it serves (Kerr, 2004).*

Despite its shortcomings the deficit model however could still be of use in science communication. Just changing from the deficit model to a more problem solving model is too simple. In the case of biomedical developments, the deficit model might be more productive than in more general communication on science and technology (Van der Sanden and Meijman, in press). When it comes to medical decisions, the audience may be more willing to have the doctor tell them what to do, and this may also be ethically more acceptable than in science communication in general (Mol, 2006).
To understand the biomedical science communication process, we need to understand how the lay audience reconstructs biomedical science in their own context and how they use this knowledge (Wynne, 1996). According to Wynne and many other authors, the science communication process is not a one-way process, but an interactive one. The level of interaction, however, depends on the way the different audiences are organized. This determines in large part how the audience uses knowledge and expertise.
The emphasis in science communication is shifting from an aim-oriented communication towards a process-oriented communication, and the process is one in which different aims and effects can be important. Communication cannot be taken as a straightforward process but is, instead, the result of a complex and self-reinforcing process (Bucchi, 2004).

In these complex communication processes, *trust* (Wynne, 1996), *credibility* and *convincing power* (Meijman, 2000) are important parameters. Convincing power is not to be seen as persuasion. Using trust and credibility, a message gains more convincing power in terms of the service needed by a target audience. As Gregory and Miller (1998) state, trust has been a key issue in research on public understanding of science. Van Gent (2000) echoes Habermas: Communication would not make any sense if the actors did not deal on a basis of trust and credibility.
Trust and credibility could be considered as the brand essence of science. These are the most important factors to communicate. They allow science to reach the lay audience and other stakeholders to start to communicate on science in many different ways with many different aims. According to the vast amount of literature on branding, credibility has a much deeper and more fundamental impact on individuals than knowledge does, and this credibility approaches our notions of knowledge. Fombrun and Van Riel (2004), for example, make the brand complexity more manageable by describing five so-called drivers for reputation: vision and leadership, financial performance, workplace environment, social responsibility, products and services, and emotional appeal. Kerr (2004) writes:

> *...The constructivist model of the public understanding of science problematizes science rather than the public. The aim of this type of research is not to improve or increase the public understanding of science, but to take the public's views seriously and to consider how best to incorporate them into policy-making. Science is not treated as if it were neutral or objective, scientific evidence is not a series of unproblematic facts, and the way in which science is organized and performed is crucial to discussions about how effective and appropriate it actually is.*

When trust and credibility result in a brand essence and image there must also be a brand identity as well, which begins from the aspects Kerr mentioned above. This identity develops from convincing power - in other words, effective communication. Convincing power, as said before, is of course not a one-way process, but must be seen as a social construct which is legitimated by the audience and society.

The notions described in the previous section make it clear that there are different levels of trust, credibility and convincing power. There cannot be one best way of biomedical science communication for every situation. ´One size fits all´ does not work. In this way, strategies of communication, such as informing, dialogue, forming and persuasion (Ruler, 1998) are needed to achieve the different aims and effects. Moreover, the communication is more process-oriented than aim-oriented. Therefore, according to Irwin (2001) information providers should not just furnish information, but should make knowledge available and provide knowledge with social availability. Wynne says that the audience itself knows what kind of information it wants and how much. It is all about negotiation (interaction) between the knowledge provider and the knowledge user. Similarly, Hanssen et al. (2003) talk about the difference between transmission and transaction. Of course, communication is always about negotiation, but this negotiation is not always on the same level. A well-informed and highly interested audience has the skills to ask questions or seek information. However, for a target group with little knowledge about S&T and little interest in it, the negotiation should start on another level and with other subjects. Bucchi (2004) states that, particularly in science communication, several empirical and theoretical contributions have critically addressed the transmission paradigm during the past two decades. A necessarily selective list of the aspects which have been pointed out includes:

1. the non-linearity of the communication process. Science communication need not necessarily spring from specialized contexts but can also originate in popular, non-specialized arenas (Lewenstein, 1995a, 1995b; Bucchi, 1996, 1998);
2. the reception of science communication is not a passive process but a complex set of active transformative processes which can, in turn, influence the core scientific debate itself (Wynne, 1989, 1995; Epstein, 1996);
3. specialist exposition of science theories and results (i.e., the source of ´transfer´ in the traditional paradigm) cannot be clearly separated from popular exposition (the target of ´transfer´), despite the fact that distinctions between the two forms of exposition are often used by scientific actors as a rhetorical strategy (Hilgartner, 1990), and;
4. the science communication process can be represented as a continuous sequence of expository levels, each gradually blending into the next, with differences in degree and not in kind, and with different levels mutually influencing one another (Cloître and Shinn, 1985; Hilgartner, 1990; Lewenstein, 1995a; Bucchi, 1996, 1998).

In conclusion, Bucchi depicts the science communication process as a continuum (Bucchi, 2004). Starting from an intra-specialist stage (communication between researchers), it moves to an inter-specialist stage, followed by a pedagogical stage, and ends in a popular stage. The closer it comes to the popular stage, the more uncertainty enters the picture, and the more the style of language changes. The context of science information changes from the research domain to the public domain.

Auweraert (2003) has taken the description of the aims of science communication together with the idea of transmission and transaction. From the ideas of Bucchi we have add non-linearity. Figure 1.3 shows how the roles relate to each other.

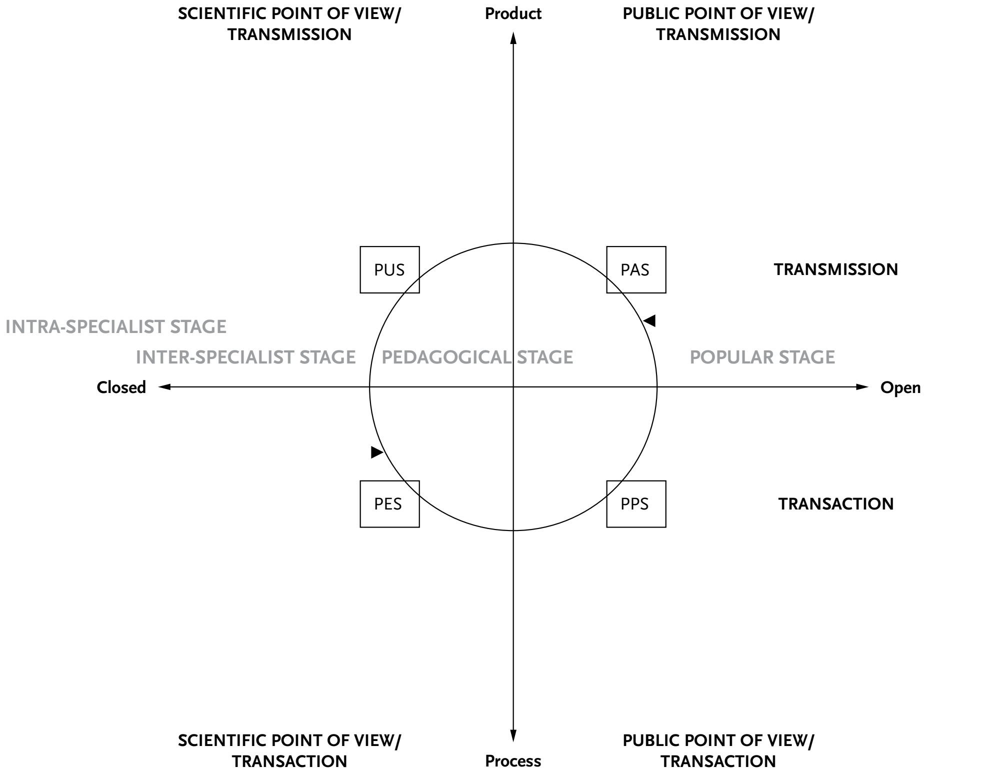

Fig. 1.3: Aims of science communication. The targets of science communication are depicted on a grid, with closed vs. open processes and product vs. process as the main parameters. Moreover, a distinction is made between transmission and transaction. PAS is an open product-oriented transmission of knowledge, in which the starting point is the public; trust and credibility are key issues. PUS is a closed product-oriented transmission, which starts from the scientific world's point of view. PES is a closed process of transaction, starting from the scientific point of view. PPS is an open process of transaction, starting from the public point of view (Auweraert, 2003). We added the arrowed circle in the middle of the grid to depict the dynamics of the process next to the dynamics on the different levels of aims already depicted by Auweraert on the grid´s axis. We also added the different stages described by Bucchi .

In summary, if we consider a non-linear, multileveled interaction between science and society, we see a complex interaction between science, science communication and the audience. Moreover, we learned from the earlier sections of this chapter that there is no specific theoretical foundation which makes all these variables manageable for practice. From different notions and perspectives it is clear that the context of the science communication process is of most importance, since it steers the communication process in terms of function and different levels. To develop a profound theoretical foundation we need to establish a context for our research. For this study we chose predictive DNA diagnostics as a context and case.

1.7 Medicalization, genetic essentialism and predictive DNA diagnostics: a case study.

Predictive DNA diagnostics can be regarded as a new medical development that strongly interacts with society. According to a report by the Dutch Health Council more than 200 genetically based diseases have been identified, among them Huntington´s chorea, sickle cell disease, hypercholesterolemia, and cystic fibrosis (Dutch Health Council, 2003). The wide societal impact of this diagnostic tool has attracted significant media attention. Dutch newspapers had headlines like, ´Heel prick sorts out choice of houses: Parents are better prepared by a broad newborn screening programme' . Scientific organizations also sent out press releases on the subject: 'DNA test promises to be a good predictive instrument for treating alcoholics' (NWO, July 2006 press release). Eclectic books on this subject have been written by the American Francis Fukuyama and the French author Michel Houellebecq. One of the leitmotivs of Houellebecq's work is the (mis)development of humankind. For example, in his latest novel The Possibility of an Island, he tells the story of Daniel and his many clones. Leschot and Mannens (2001) wrote a book Genen in beweging: erfelijkheid in de 21ste eeuw on hereditary health issues in the 21st century, which clearly explains the main issues in genetic testing. Genomics in general and genetic testing in particular are already popular products. The consolidation of DNA diagnostics into society is interesting because of the speed at which DNA diagnostics was introduced and the fact that this had made it impossible to miss (Nelis, 1998).
The lay audience's knowledge gap about genetic diseases, however, has been shown to be quite large (Andrykowski et al., 1997; Donovan and Tucker, 2000; Eurobarometer, 2000). For example, studies in the US show that there is a need for information on hereditary cancer. In the Netherlands, 40% of those surveyed did not know that plants have genes, and 10% did not know that there is a possibility of testing for Down syndrome in early pregnancy. Moreover, medical genetics and genomics are more positively perceived than genetics and genomics with an agricultural application (Condit, 2001; Van Dam and De Vriend, 2002). Though much information is available on the Internet, the lay audience does not always know how reliable this information is (Taylor and Leitman, 2002).
Commercially available predictive tests can be carried out at home (Parthasaranthy, 2007), which makes predictive DNA diagnostics a medical development that differs from developments in medical imaging techniques, for example, which is almost always carried out in the realm of professional medical practice and not in a public or private space.
In addition to the clear difference between predictive DNA diagnostics and medical imaging on a societal level there are similarities as well. As a result of new technologies, the body can be measured in many different ways. But as Van Dijck (2001) asks, do all of these techniques make the body more transparent? The same could be asked about predictive DNA testing. Discussing MRI scans, Van Dijck says that that technique makes the body more transparent but at the same time more technical, and for that reason the body becomes more occult. Consumers are not trained to analyse and evaluate medical visualization, so they must place more trust in the practitioner. New techniques bring new ethical constraints. This is also true for biomedical science communication on predictive DNA diagnostics, where an overload of information could cause needless anxiety. All this makes the case of predictive DNA diagnostics an interesting context in which to study the theoretical possibilities for effective biomedical science communication. In the next section we start from a wider societal perspective and then focus on predictive DNA diagnostics. Herewith we return to biomedical science communication.

Medicalization and genetic essentialism

The genetic basis of diseases is assuming increasing importance. Contemporary Western society has medicalized quite rapidly. Social scientists and other analysts have written about medicalization since the 1970s (Conrad, 2005). The essence of medicalization became a question of definition: defining a problem in medical terms, usually as an illness disorder, or using a medical intervention to treat it. While early critics of medicalization focused on psychiatry or on a more general notion of medical imperialism (Illich, 1975), social scientists began to examine the processes of medicalization and the expanding realm of medicine (Freidson, 1970; Zola, 1972).
Conrad depicts three factors underlying this development. First, there was the power and authority of the medical profession; the profession itself and the expansion of medical jurisdiction were prime movers for medicalization. Second, medicalization sometimes occurred as a result of the activities of social movements and interest groups. In these cases, organized efforts were made to champion a medical definition of a problem or to promote a medical diagnosis. Third, organizations and professions promulgated medicalization, as was the case with obstetricians and the demise of midwives (Wertz and Wertz, 1998). This trend towards medicalization, the transformation of the patient to consumer, and the developments in genetic research are important parts of the context of biomedical science communication. As Conrad (2005) writes:

> *Genetics has become a cutting edge of medical knowledge and has moved to the centre of medical and public discourse about illness and health (Conrad, 1999). The biotechnology industry has had starts and stops, but it promises a genomic, pharmaceutical, and technological future that may revolutionize health care (Fukuyama, 2002).*

Within the concept of medicalization, genetic essentialism is central to the development of genetic research and its impact on society. Nelkin and Lindee (1995) write:

> *The status of the gene - as a deterministic agent, a blueprint, a basis for social relations, and a source of good and evil – promises a reassuring certainty, order, predictability and control.*

Genetic essentialism has made several commercial developments possible, even as it is itself shaped by commercial activities and the role of patients as consumers. For example, consumer-patients are now also courted by the pharmaceutical industry. According to Conrad, drug companies now spend nearly as much on direct-to-consumer advertising as on advertising to physicians in medical journals. This is about marketing diseases, and then selling drugs to treat those diseases. Conrad (2005) writes:

> *The engines behind increasing medicalization are shifting from the medical profession, inter-professional or organizational contests, and social movements and interest groups to biotechnology, consumers, and managed care organizations.*

In addition to the industry's marketing efforts, there is also an effort on the part of the public to understand developments in genetic research. Guidelines and safeguards should be established to ensure that if testing takes place, it is done in an ethical and beneficial manner, with informed consent, and not driven solely by commercial aims (Baird, 2002). DISCERN (http://www.discern-genetics.org) and ACCE (http://www.cdc.gov/genomics/gtesting/ACCE.htm) offer quality-appraisal systems for genetic tests to be used by the public as well showing guidelines and safeguards (see Box 1.4).

Box 1.4:

DISCERN GENETICS - as the website describes - has been developed to ensure that there is an accessible appraisal tool for patients and other users of information about genetic screening and testing, and that information providers and producers have access to well-researched guidelines. One of the aims of DISCERN is to enable information providers and users to judge the quality of information on genetic tests that is available to the public and facilitate the production of new, high-quality, evidence-based public health information on genetic testing by setting standards and providing a reference point for authors (www.discern.org.uk).
ACCE, which takes its name from the four components of evaluation - analytic validity, clinical validity, clinical utility and associated ethical, legal and social implications - is a process model for evaluating data on emerging genetic tests. The process includes collecting, evaluating, interpreting, and reporting data about DNA (and related) testing for disorders with a genetic component (www.cdc.gov/genomics/gtesting/acce/fbr.htm).

These appraisal systems provide insights into the usefulness of specific tests and the conditions needed for effective biomedical science communication on predictive DNA diagnostics, such as the ethical, legal and social implications. Therefore, as the DISCERN website describes, it enables the public and professionals to debate and to share decision making, and provides a mechanism for promoting discussions between professionals and the public on making informed choices about genetic screening and testing.
Both examples are well-designed and sophisticated information systems and could be part of an effective communication strategy on predictive DNA diagnostics. Neither DISCERN nor ACCE, however, provide insight into the development of a process or strategy of effective communication with an audience on this issue; a process or strategy in which, for example, the notions of the audience are taken into account. The public should play an important role in such a communication process or strategy in terms of transaction and negotiation of meaning, as described earlier in this chapter. On this subject, Kerr (2004) writes:

> *...There is a considerable body of work on the public understanding of genetics. This is largely driven by government officials´ and scientific professionals´ concerns about the lack of the public trust in their work. They are keen to know about the public understanding of genetics and what influences it, so that they act upon the results to clarify misapprehensions and foster public trust. Much of this work is rather pedestrian and conservative: focused upon what the public do not know about the technicalities of genetics. However, consultation and research exercises are increasingly concerned with public perceptions of scientific practice in its broadest sense, and have begun to take seriously public concerns about accountability and transparency in policy-making in this area.*

In the next section we focus on predictive DNA diagnostics as a specific medical development in the context of genetic essentialism and medicalization.

Predictive DNA diagnostics: a case study

DNA diagnostics is becoming an increasingly important diagnostic tool for genetic diseases. It can be seen as one of the main issues of the modern era (Galjaard, 1996; Nelis, 1998; Baird, 2002; Caskey, 1992; Health Council of the Netherlands, 2003). DNA technology is increasingly being used in personal medicine, for example with genetic tests indicating how a patient will metabolize a drug used to determine its dosage (Church, 2006).

Research on predictive DNA diagnostics and its implications for individuals and society has increased since the introduction of the polymerase chain reaction (PCR), a technique that makes it possible to replicate a specific piece of DNA. This was an enabling technology for DNA diagnostics (Leschot and Mannens, 2001), and there is now a flood of information about faulty genes implicated in virtually every major human disease, including diabetes, cancer, and asthma. It seems that almost every week a new disease gene is discovered (Watson, 2000). Many aspects of genetic testing are being researched. For example, in HNPCC, Molecular and Clinical Dilemmas, Wagner (2005) investigates the biological foundation of the DNA test, as does Waas (2006) in Matrix metalloproteinases in human colorectal cancer: A study with the emphasis on the predictive value of gelatinase activity.
One might ask: how much information about genetic screening does the public need? And what claims can be made? It is important that the public has a realistic view of the potential and expectations for this technology (Tijmstra, 2002). For example, in the case of breast cancer screening, a first step could be asking the lay audience what they want to know, instead of giving them the information immediately (Van Maanen, 2002). As said before, systems such as those provided by DISCERN and ACCE do provide information and can be used to appraise information quality, but this information does not necessarily fit the target audience or develop a social basis in terms of trust, credibility and convincing power. Biomedical science communication on predictive DNA diagnostics is complex on an informational level (Nillesen´s flow of information, section 1.4) and a communicational level (Nillesen´s flow of influence, section 1.4).

Several different genes have been found that indicate susceptibility to particular disorders, and some individuals may have more than one of these genes, each of which changes the person's risk to a different extent (Baird, 2002). However, Wagner (2005) also considers the psychological impact:

> *The challenge for clinical geneticists and others working in the field of hereditary cancer, is to supply optimal multidisciplinary care in the short and long term, to develop non-invasive screening and prevention options, and to contribute to a social climate necessary for the individuals to make free and personal though educated choices relative to testing for genetic risk factors.*

Timman (2005) also deals with psychological consequences in *Huntington's disease: Psychological aspects of predictive testing*, as does Hendriks (2005) in *Familiar arrhythmia: The psychological aspects of genetic testing.*
As Timman says:

> *HD [Huntington's disease] had the dubious honour to secede from the unknown rare diseases, and to become the paradigm that should provide the knowledge and experience to establish predictive testing programmes. This development has not only affected the medical field. Its far-reaching consequences made predictive testing a matter of social, political and economic forces and made HD an important model on which the establishment of many other testing programmes could be based[...].The risk of an adverse emotional response was considered the single greatest risk of predictive testing. Serious concerns were raised about the psychological consequences of the results of predictive testing for HD, with the possibility of an increase in deaths by suicide among identified carriers of the gene.*

The psychological issues are such that one should even consider whether tests for incurable diseases should be conducted at all (Galjaard, 1996; Health Council of the Netherlands, 2003). As was mentioned, it can even lead to genetic essentialism. If we accept that all people are unequal, the right and the ability to make individual choices should be enhanced (Galjaard, 1996). This concern clearly calls for effective biomedical science communication on this subject. Leschot and Mannes (2001) cite the Council of Europe Convention on Human Rights and Biomedicine (1996):

> *Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes and subject to appropriate genetic counselling (Article 12).*

These concerns already played a role in the 20th century. Snelders et al. (2007) write that communication on cancer heredity was silenced because the Dutch government was afraid of stigmatization, and of increasing feelings of anxiety and fatalism among affected individuals, which might have influenced public participation in screening programmes. To generate insight into these information communication processes a theoretical foundation for biomedical science communication on predictive DNA diagnostics is needed, not only for the field of biomedical science communication but also for the specific developments in predictive DNA testing. Predictive DNA testing functions as a case study for our research, but not solely that, because the results of our research are directly applicable.
The Health Council of the Netherlands has written several white papers on this subject. Erfelijkheid: wetenschap en maatschappij (Heridity: science and society; 1989); Publiekskennis genetica (Public awareness about genetics; 2003); Proefbevolkingsonderzoek naar darmkanker (2005, in Dutch). These papers identifie the following goals:

1. knowledge about hereditary diseases: a) should be enhanced in medical practice, and b) should be enhanced in public communication;
2. there should be no barriers to knowledge: everyone should be able to get information about genetic diseases and tests;
3. quality standards for clinical genetic research should be enforced. Commercially available genetic tests should not be used at home, but should be administered in professional medical settings.

According to the Health Council, people ask for a test when:

1. the parents already have a child with a genetic abnormality;
2. genetic abnormalities run within the family;
3. one of the parents has an genetic abnormality;
4. there is a blood tie between the parents.

Since it isn't clear to the lay audience what genetic counsellors do, effective communication on this subject should be emphasized, and genetic testing should become a topic of public debate. The lay audience should have all the information necessary to 1) have insight into the quality of genetic testing, 2) understand hereditary factors, 3) know how to behave, and 4) know how to cope. This information should be given in a non-directive manner. And, finally, the public needs to know that the effect of genes is interconnected with diet and lifestyle. This knowledge underlines the responsibility of the individual to make proper choices. In addition to knowing the facts, the lay audience needs to know how to look for information.
The possibility of taking a diagnostic test is important, the Health Council states. When it comes to screening the population, healthy people become worried or developing feelings of insecurity. In addition, some results could be false positives. To improve lay knowledge about genetics and genomics, attention needs to be paid to:

1. primary and secondary education;
2. public communication, and;
3. the position of the general practitioner (Burke and Emery, 2002).

The lay audience's knowledge of the following subjects needs to be improved :

1. genetic variance;
2. the interaction between genes and the environment (which has to counter weigh deterministic thoughts);
3. how to deal with change and probabilities;
4. how to get needed information.

All of the above is about disseminating information on predictive DNA diagnostics in a complex environment that includes medical high high-tech and societal developments. From the literature on communication science in general and biomedical science communication in particular, we learned that effective communication in a complex environment is itself complex most of the time, due to the many variables associated with the process. Miller and Kimmel's model of medical science communication forms a starting point for research on effectiveness in a complex context but it needs to be expanded. A more profound theoretical foundation is needed to learn how all of the different variables described in this chapter work together in a process of effective biomedical science communication on predictive DNA diagnostics. How can these variables be managed? In this chapter we have looked for a theoretical foundation in the history of science communication, science communication in general, communication science, the developments in public communication, but we did not find a sufficient basis for a profound theoretical foundation for effective biomedical science communication. As we have said, we may learn from related communication research fields or communication related research fields within the biomedical domain, which of the theories from communication science should be modified in what way to the context of predictive DNA diagnostics. What is the best way to make use of the different concepts, theories, models, constructs and variables in an effective biomedical science communication process? This question has guided the formulation of our research question, in the following section.

1.8 Research problem and questions

As far as is known, the effectiveness of science communication in general and biomedical science communication in particular is low. Only a few specific target audiences understand the impact, urgency or necessity of biomedical science. Due to developments such as predictive DNA diagnostics, though, public understanding of these developments has become important for society as a whole. This means that the effectiveness of biomedical science communication should be improved. Therefore, practitioners need to know which variables of the communication process are the most critical, and which criteria can be used to measure the enhanced effectiveness of communication. At present, there is almost no theoretical foundation for biomedical science communication, or for science communication in general. Although science communication practitioners are enthusiastic, fundamental research tends to be cautious. This can also be seen at the PCST conferences (http://www.upf.edu/pcstacademy/PCST_Network/network.html), where best practices are fully discussed and displayed, but where scientific research is still at the fringes. Of course, the exchange of good ideas must continue, but these developments can be enhanced by a theoretical foundation, which takes into account all the variables mentioned in this chapter, such as trust, credibility, convincing power, aims, strategy, etc. A theoretical framework can form a foundation that sets priorities and that holds together all the relevant variables and the supporting theories, models, constructs and concepts[5] most likely to be needed in developing an effective biomedical science communication process on predictive DNA diagnostics. In this exploratory descriptive research we aim to construct such a theoretical framework by systematically searching, sorting and discussing the new variables[6] most likely to be of use in biomedical science communication on predictive DNA diagnostics. Therefore, we focus on health communication, medical psychology and (medical) commercial advertising. The central problem here is what biomedical science communication can learn from health communication, medical psychology, and from (medical) commercial communication (advertising).

[5] *Concepts* are the major components of a theory; they are the building blocks or primary elements of a theory. Concepts can vary in their extent; they are the building blocks or primary elements of a theory (Kerlinger, 1986 in Glanz et al., 2002). [...] When concepts have been developed or adopted for use in a particular theory, they are called constructs (Kerlinger, 1986 in Glanz et al., 2002).

[6] *Variables* are the empirical counterparts to or operational forms of constructs. They specify how a construct is to be measured in a specific situation. It is important to keep in mind that variables should be matched to constructs when identifying what should be assessed in the evaluation of a theory-driven programme (Glanz et al., 2002).

Which variables contribute to the effectiveness of biomedical science communication in this complex environment? In order to address this question, the biomedical science communication process is divided into structure, process, outcome (Donabedian, 1980), and context. We chose these factors to evaluate because they are developed from the medical context and meant to function on an abstract level. If we had used evaluation models obtained from the communication science domain we might have had problems analysing medical psychology, because the analytical grid is either too small or too wide. Why not develop an evaluation framework for biomedical science communication first? In order to do so, one needs a theoretical foundation for biomedical science communication in order to know which variables and criteria should be evaluated. By using a meta-frame such as Donebedian describes, the level of analysis corresponds to the state of development of biomedical science communication. The different fields cited above as comparisons can be included in this wide analytical frame. We have added context because it is a primary condition for understanding the effectiveness of communication processes. Other important conditions are explicitly mentioned in structure, process and outcome.
What are the three scientific domains likely to contribute? Health communication: Health communication is the domain which is practically and theoretically the closest to biomedical science communication. However, the domain differs (as described in section 1.1, it is not directed toward biomedical research), and that forms the starting point for comparing theories. Medical psychology: In general, psychology is one of the theoretical pillars of communication science, and medical psychology is one of the theoretical pillars of biomedical science communication. However, the theoretical level differs, which means that theories have to be translated to the field of biomedical science communication. (Medical) commercial communication (advertising): This communication domain differs in function from biomedical science communication. Despite this, theories might be translated to the field of biomedical science communication. Of course, with translation there are different accents on structure, process, outcome and context. One cannot choose a domain that differs from biomedical science communication only in structure. Structure, process, outcome and context are too interwoven to permit this.

1.8.1 Sender or target-group orientation

The primary focus of this thesis is on an effective process of science communication. Sender-oriented and target-group oriented communication, and the theories developed from these approaches, are equally applicable to the process. From a practical point of view, this thesis assumes the perspective of the communication professional, with a sender-oriented communication approach. What theoretical foundation can the communication professional use to develop an effective communication process? There are two reasons for this exploratory descriptive approach from this angle:

1. One could interview an audience to ask which elements are important to them in the process of effective biomedical science communication on predictive DNA diagnostics. From these data one could develop new theories for effective biomedical science communication on predictive DNA diagnostics. We have chosen to start from the theoretical side to research a profound theoretical basis for effective biomedical science communication. This originates from the idea that a science communication professional can obtain relevant information for his own practice by reading literature on the subject. In practice there has not been time for conducting surveys, as we stated in our foreword. Moreover, when analysing from this viewpoint the theoretical position of biomedical science communication becomes clear regarding health communication, medical psychology and commercial advertising. Conclusions on this subject may support practice in making choices about which communication modality best fits their communication targets. The next step would be designing a biomedical science communication research programme, which should be pre-tested with a lay audience target group;

2 The target group's knowledge is increasingly important in biomedical science communication. As this chapter made clear, the process of science communication has so many levels that the beliefs and opinions of the target audience will be incorporated, one way or another, and probably also from the surveys carried out within the domains studied in this thesis. Sender and receiver are viewpoints for the same process.

All the above leads to the following assumption:

By comparing biomedical science communication to health communication, medical psychology and commercial medical advertising and identifying the variables that govern effectiveness, it is possible to formulate a theoretical framework for effective biomedical science communication on predictive DNA diagnostics. Moreover, comparing these domains clarifies the position of biomedical science communication.

The need for a theoretical foundation for biomedical science communication has been described. The position of biomedical science is important to further theoretical development: Is biomedical science communication a subordinate field, or does it enhance or steer other fields of communication? (See Fig.1.4.)

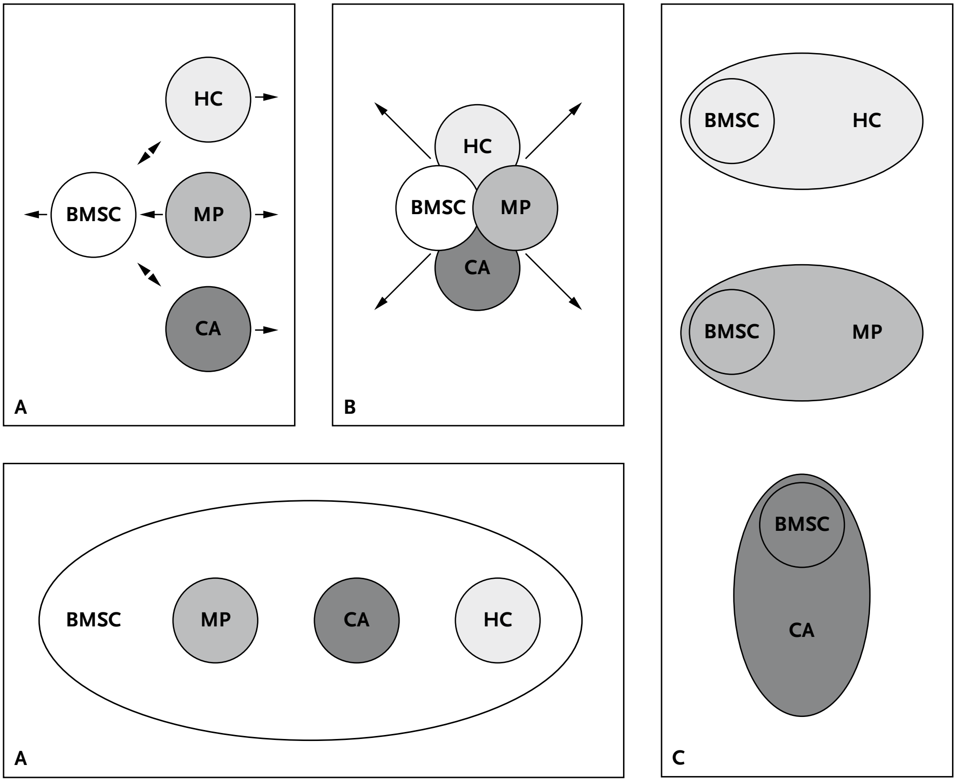

Fig. 1.4: The different possibilities for organizing the different modalities. In each chapter, a conclusion based on these four possibilities will be drawn. A: Biomedical science communication (BMSC), health communication (HC), medical psychology (MP) and commercial advertising (CA) are domains of knowledge that are linked together in different phases of the communication process. They influence each other, but in theory they are separate. B: All domains start from the same theoretical ground but do not influence each other in their separate processes. C: BMSC is a part of the domains of HC, MP and CA. BMSC is therefore totally influenced by the separate domains, which do not influence each other. D: MP, CA and HC are domains within the realm of BMSC. MP, CA, and HC influence BMSC and, probably by operating in the same domain, they influence each other.

1.8.2 Aims of research

From the research problem and assumptions, the following research aims can be formulated:

1. to define a theoretical framework for effective biomedical science communication processes for lay audiences in the field of predictive DNA diagnostics;
2. to gain insight into the position of biomedical science communication in the (science) communication domain and in the other domains considered in this study;
3. to build an instrument based on the theoretical findings for the biomedical science communication practitioner in the practice of predictive DNA diagnostics;
4. to gain insight into the distance between the theory and practice of biomedical science communication on predictive DNA diagnostics from a theoretical perspective.

1.8.3 Research questions

To accomplish the aim of this study, the following main research question was formulated:

> *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?*

This question can be divided into a number of manageable sub-research questions:

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? How might they contribute to the theoretical framing of biomedical science communication on predictive DNA diagnostics?;
2. is it possible to build a valid framework for effective biomedical science communication on predictive DNA diagnostics from the results of this comparative study?;
3. what is the position of biomedical science communication within the communication domain?;
4. is this framework realistic from a practical perspective? In other words, what is the distance between theory and practice?

1.8.4 Description of variables:

1. the **structure** of the biomedical science communication process includes the actors, the organizations, the buildings, the printed logos. All of these are tangible (Donabedian, 1980), and in a sense even the message is tangible;
2. the **process** includes everything that is fluid: the message, which changes in time and place; the different actors, who get different roles over time. Everything at the level of interactivity belongs to the process (Donabedian, 1980);
3. the **outcome** includes the aims and effects, in this case formulated for predictive DNA diagnostics. (Donabedian, 1980);
4. the **context** is formed by the environment (physical, mental and social) in which the communication processes occur. We added context to the variables Donabedian described;
5. **effectiveness** is the most complex variable, since it depends on many criteria in terms of structure, process, outcome and context. Effectiveness is the variable that incorporates the different theories of public communication;
6. the **moral** variable is formed by the scientific method, scientific values and societal values in general, and the values regarding medical issues in particular.

Chapter 2 explains the methodology of translational systematic literature research, as well as the different orders of comparison in this thesis.