Summary
Before you start reading
The summary of this dissertation begins by presenting the essence of the conclusions. The more time the reader is prepared to invest, the more these conclusions unfold. It is interesting to see how conclusions naturally give rise to new questions. In our opinion, this is how in-depth exploration and scientific research operates.

The dissertation in 5 minutes: the general outline
In this dissertation, we describe a theoretical framework and an instrument (a questionnaire and the setting up of a database for systematically developed review articles) derived from it for the development and design of a manageable process of biomedical science communication on the subject of predictive DNA diagnostics.

The theoretical framework and the instrument are based on theories from various areas of communication or various fields related to communication. The focus is on identifying factors that determine the success or failure of communication processes within health communication, medical psychology and (medical) commercial communication (advertising). The communication elements of structure, process, outcome and context formed the analytical framework, while the developments in predictive DNA diagnostics formed the reference point. In addition to producing the theoretical framework and the instrument, the results of this research also serve as the basis for studying the position of biomedical science communication in relation to the other fields.

The new insights borrowed from various fields have extended the theoretical conceptual apparatus for biomedical science communication. Using the theoretical framework, it is now possible to pose far more specific research and design questions in relation to the various elements in the process. In the questionnaire, communication professionals and policymakers in the area of predictive DNA diagnostics reflected on a case study about lung cancer and predictive DNA diagnostics. Both individually and collectively, the respondents came to the conclusion that the instrument is of use to professionals who have to think in highly abstract terms about the design of biomedical communication activities, and new activities in particular. The theoretical framework and the instrument provide insight into the communication process, make it manageable and possibly effective for the future. Effectiveness can only be tested if the framework and the instrument are used and evaluated in practice.

The questionnaire helps professionals to ask questions and take a critical view of the process. The review articles, which are intended for inclusion in a database, lead to evidence-based biomedical science communication and support the professional in expanding the range of options available for designing a biomedical science communication process. The aim is to achieve a simple method of ensuring the availability of relevant but above all valid information on communication research; in other words research that carries considerable weight. We believe that the theoretical framework and the instrument developed in this study can also be extrapolated to science communication in general.

The information above effectively answers the first research question. With regard to the second research question on the position of biomedical science communication, we have identified three factors that are crucial in determining which communication domain takes precedence under a given set of circumstances: the context, the objective or the emotional distance of the target group to the subject (in the case of this research, the genetic disorder). The moment and the situation (context, objective and emotional distance) determine the structure, the process and the outcome. Context is an important addition to the analytical instrument developed by Donabedian (1980). If the emotional distance is long because the target group is not personally involved, if the objective is to inform since persuasion on ethical grounds is not desirable and if the context is not compelling, then biomedical science communication is the most appropriate option for communicating with the target group. Elements of health communication can also play a part in such circumstances, of course, but the set of communication tools used in the first instance belongs to the domain of biomedical science communication.
The dissertation in 10 minutes: the method

In this exploratory descriptive study, we explored various fields by means of a systematic literature survey. In the medical domain, this approach is better known as the methodological basis for evidence-based medicine. The relevance and validity of the literature are central to this approach; these combine to determine the weight of the study. In the conclusions to the study based on the literature survey, it is important to include the literature that is most relevant (appropriate to the research question?) and valid (studied in the correct way?), since such literature makes the strongest contribution (carries the greatest weight) in serving as the foundation for a robust conclusion. An essay, however groundbreaking, ultimately has less resonance than a randomised clinical trial when it comes to the robustness of the conclusions. In this analysis, we make an additional distinction between consolidated literature (books and manuals in the catalogues of universities and other academic libraries) and unconsolidated literature (articles in scientific journals available through a large number of databases).

However, time restrictions and other practical limitations mean that, of course, we have not been able to read and assess all of the literature with the most resonance or to assess these works in terms of their relevance and validity. Experts and researchers who specialise in the fields studied in this dissertation will undoubtedly be able to add numerous other examples. The great methodological benefit is mainly to be found in the transparent approach taken in selecting the literature, in detailing the use to which it was put and in describing how it relates to the final conclusions of this study. It is this transparency that enables us to adequately compensate for the various blind spots in the analysis.

The study as a whole is comparative in nature. When engaged in a comparative study, the danger of comparing apples and oranges must always be addressed. In other words, does it or does it not make sense to compare the issues at the heart of your research? Using Gödel’s theorem and the recent study by Verdoes (2005) relating to the comparison of economic theories, we have created a formal logical and methodological framework for comparing different fields with one another.

We limited ourselves in terms of time and the scope of our literature survey, and we developed a rationale for conducting comparative systematic literature research. The decision to develop a method in this way was justified by the fact that biomedical science communication is still in an exploratory phase. The practice of biomedical science communication is diffuse and so too is the research. There is no established methodological practice. Indeed, it is by identifying part of the methodological basis of the discipline that we hope this dissertation will contribute to determining a number of different lines of research. The results of this dissertation make it possible to articulate new research questions that contribute towards a further theoretical development of biomedical science communication: a theoretical development that supports practical application and vice versa. The following section contains separate summaries of each chapter.

The dissertation in 35 minutes: chapter by chapter

This section of the summary presents the main conclusions of the individual chapters. Naturally, these conclusions form the basis for the description that constitutes the first five minutes of this summary. The second chapter (Research Methods) and the final chapter (Discussion and Conclusion) have not been included in this overview, as the most important aspects of the research method and the conclusions have already been presented in the previous sections. However, we will return to the agenda for future research in the final section of the summary.
Chapter 1: introduction

Medical subjects represent a separate category of scientific development when it comes to communicating with the general public. This can be attributed to the shorter emotional distance between the public and medical issues. A new machine for the packaging industry is bound to be further removed from the general public than a breakthrough in the treatment of cancer. The discussion about the demise of Pluto’s planetary status is far less emotionally charged than the discussion on whether it is worthwhile to carry out a PKU test on babies or to conduct a population study on bowel cancer. Climate research occupies the middle ground in this emotional spectrum. The medicalisation of society (“playing doctor” using widely available do-it-yourself tests) has its own dynamic due to emotional involvement on a number of levels, involvement which can reach a hysterical pitch at times.

In relation to science communication in general, and biomedical science communication in particular, theoretical development is in its infancy. Miller and Kimmel (2002) are among the few to have developed models in the field of biomedical communication, based on a number of surveys carried out in the United States. Unfortunately these models fall short when it comes to understanding the interaction between different variables they describe. The academic literature on science communication consists of describing a large number of best practices, as well as non-systematic evaluations, media analyses and essays. Of course, every publication and conference contribution adds value to the field but it is difficult to pinpoint trends in research methods and in the issues dealt with. In this dissertation, we make a specific proposal regarding the link between theory and practice, in order to at least formulate research questions arising from best practices and move in the direction of theory and vice versa.

Of the trends that are central to science communication, two-way communication, interactivity and dialogue are among the few recurring themes. Much is written about the importance of interactivity and dialogue but there is hardly any evidence of valid theoretical argumentation that can help those in the field to make choices when developing an effective process. Books (consolidated literature) published on the subject of science communication are usually kaleidoscopic in nature and are therefore symptomatic of the development within the discipline itself. While it is, of course, true to say that these books already contain a number of the theoretical building blocks, science communication in general and biomedical science communication in particular are still very much in a phase where theory is only taking shape. From the special position that medical issues occupy in the public domain, the theoretical infancy of biomedical science communication, the following research question has been 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?

Chapter 3: health communication

Health communication is the communicative domain that is closest to biomedical science communication about predictive DNA diagnostics. Using consolidated literature, we have been able to add three modalities within biomedical science communication: biomedical science promotion, biomedical science education and prevention of shortfall in biomedical science information. Within these modalities, the objectives and effects described in science communication have a role to play. These health communication objectives are meaningful to the individual in terms of the meaning of knowledge, the growth of knowledge and the use of knowledge. Concepts, theories, models, constructs and variables borrowed from health communication considerably expand the conceptual apparatus of biomedical science communication. The theories used within health communication are also applicable within biomedical science communication. For example, the Health Belief Model and Protection Motivation Theory make use of concepts such as
self-efficacy and health locus of control. The former concerns an individual's own effectiveness. Although the concept has already been widely discussed, it is a new addition to the domain of biomedical science communication. Self-efficacy centres on the question of whether people think themselves capable of understanding or otherwise giving meaning to all manner of aspects relating to predictive DNA diagnostics. Health locus of control or, in the case of biomedical science communication, knowledge locus of control, provides an insight into what individuals see as the source of knowledge. Do they think that they themselves have to seek out information (internal locus of control) or that they should be supplied with this information (external locus of control)? The answer to this question determines the direction of the communication process.

Another striking result is the existence of a research liaison officer within the practice of health communication. This liaison officer is responsible for making research results on health communication available (i.e. making them meaningful and manageable) to the practice of health communication. The connection between theory and practice is not made automatically. There are no conferences, for example, where researchers and professionals can meet or where this question regarding the connection between theory and practice is clearly asked. The same is true of the practice of biomedical communication in particular and science communication in general. A liaison officer contributes towards solving this problem.

Chapter 3 ends with a flow diagram (theoretical framework step 1) in which the various findings are presented. It has become clear that the conceptual apparatus available to biomedical science communication has been considerably expanded. This expansion contributes to the design of a more readily manageable process for biomedical science communication. The big problem now is, where do the points of emphasis lie? How does the colour of this model change in relation to the type of genetic disorder? Knowledge gleaned from the field of medical psychology can help provide the answer. This is the subject of Chapter 4.

**Chapter 4: medical psychology**

Medical psychology can be regarded as a discipline at the basis of biomedical science communication, analogous to the position of psychology in relation to communication in general. Within the framework of predictive DNA diagnostics, genetic counselling also plays an important role as a practical application of medical psychological knowledge.

Many of the theories which are also described in the framework of health communication appear in the consolidated literature as well. A number of aspects which are crucial to biomedical science communication can, however, be derived directly from medical psychology. These include such concepts as therapy compliance, fear, anxiety, empowerment and the irreversibility of a genetic disorder.

Within medical psychology, there is a view that therapy compliance can be improved if patients become aware that they themselves are responsible for improving their situation. One of the methods of achieving this is to ask questions instead of giving information or solutions. The same method can also be useful in biomedical science communication in relation to target groups that are further removed from a subject. As long as they do not see a subject as their problem or deserving of their attention, communication in the sense of providing information will not be effective in the least.

Whether people start to feel responsible depends to a large extent on the emotional distance between them and the subject. Does the disorder affect me personally or someone I know? This is related to variables such as anxiety and fear. In turn, anxiety and fear depend on the extent to which the disorder is irreversible. Level of involvement, anxiety and irreversibility are closely related and combine to form a focal point in people's well-being and in their motivation to either use, store, take note of or indeed disregard knowledge. Within biomedical science communication about predictive DNA diagnostics, these same insights are significant for the design of the communication process and the message.

In a communicametrical comparison that seeks to measure communication and show the sequence of and mutual relationship between constructs and variables, it becomes clear how a communication process could
look like. A comparison of this type at least makes the complexity of the process and the associated variables manageable. Using unconsolidated literature, it then becomes clear which of these variables have been studied in the most valid way and which can best be utilized in the biomedical domain. The notion of not giving information but communicating about the preconditions for knowledge instead is examined in greater detail in the next chapter, on the subject of commercial information.

Chapter 5: (medical) commercial communication
Commercial communication (advertising) has a long tradition, especially within the medical world. It is therefore regrettable that more relationships have not been forged between the various fields over the years. While social marketing is a field that plays an acknowledged role within health communication, social marketing is still a domain distinct from advertising theory. Fennis (1999) has developed advertising theory for health communication on TV in greater depth. Central to his approach is the Elaboration Likelihood Model (ELM) and concepts such as product and brand experience. To our knowledge, these are not subjects to be found in social marketing. Advertising is therefore much more of a communication discipline than a marketing discipline. The ‘P’ for promotion has therefore been adopted by marketing communication within marketing. However, this chapter is not concerned with the relationship between marketing, marketing communication and advertising. We are primarily interested in the theories and concepts of advertising theory.

As mentioned above, Fennis has given ELM a place within health communication. In this study, we have done the same for biomedical science communication. This reveals that groups who are far removed from the subject (long emotional distance) can best be approached by means of issue-relevant information. In an analogy with advertising, this target group is not interested in information on predictive DNA diagnostics but may well be interested in the status attached to knowledge of this subject. This can be alluded to in the first instance.

On the basis of the consolidated literature, we can use the image of a set of scales which give a precise reading of the balance between all of the elements of the message which can make the difference for the target group in terms of taking action or devoting attention to a particular issue. The image of the scales has also been borrowed from the literature on advertising. The heaviest weight on the scales is determined by prejudices, notions and cultural aspects relating to the world of medicine. These elements not only determine whether the scale tips, but also the direction in which it tips. This can be described in terms of “indifferent balance”, a concept derived from classical mechanics, and which refers to a balance that can repeatedly take on another form or position. The starting point for designing a communication process can therefore be different each time. Significantly expanding the various possibilities derived from advertising makes the communication process for biomedical science communication more manageable.

Based on the findings in Chapters 3, 4 and 5, a questionnaire was drawn up and presented to professionals (in the fields of communication and policy) from the world of genetic testing and population studies. This was done to determine whether the concepts and theories were recognisable and manageable in practice. This is the subject of Chapter 6.

Chapter 6: reflection from the practical side
The instrument that we developed in cooperation with the Centrum voor Verslavings Onderzoek (CVO, Centre for Addiction Research, whose expertise includes drawing up questionnaires) can be regarded as an instrument for Biomedical Science Communication Process Assessment (BSCPA).

The reflection process was structured into three phases: 1) individual completion of the questionnaire based on a fictive case study about a predictive test for lung cancer; 2) an interview conducted by an interviewer from CVO, with questions about the circumstances and reasons behind the answers given in the questionnaire (how and why). Was the questionnaire clear, are there any elements that should be added?; 3) a group meeting in which the main conclusions are discussed once again. The most important result is that the professionals see
the instrument as a tool for formulating a number of important questions in the light of one’s own objectives during the developmental phase of the campaign. The instrument helps estimate knowledge deficiencies and their consequences for the communication process as a whole. Questions for future research are: is it possible to extend this instrument with modules (questions) from another domain? How can this instrument be developed further in cooperation with the field?

The dissertation in 45 minutes: the future
The theoretical framework and the instrument on which it is based and that was tested in practice, provide greater insight into the practice of biomedical science communication in relation to DNA diagnostics and make it manageable by increasing the possible approaches and scope for action. In order to determine effectiveness, evaluation research is needed in which the use of the instrument is tested in practice. In the conclusion of the dissertation, we therefore propose an agenda for future research which echoes this demand for evaluation research. Other questions deal with further development of concepts, theories, models, constructs and variables for biomedical science communication along the lines of constructs such as self efficacy and locus of control; the design of the message and the communication process, and possible design heuristics for an effective biomedical communication process. While it is true that the theoretical framework and the instrument do not provide any ready-made solutions as regards effectiveness, they do ask clear questions about the design and optimisation of communication processes. In the meantime, the instrument is being adapted for the web, where it can be tested and expanded under a variety of conditions. This has transformed it into an actual bridge between theory and practice, one that is based on both theory and practice.

In this study we have, as it were, cut to the chase in the development of biomedical science communication. As long ago as 1950 or thereabouts, people were talking about the need for interactivity in health communication. The fact that it took 40 years for this challenge to be taken up by science communication in general can be regarded as a missed opportunity. It is to be hoped that the theoretical framework, the instrument and thinking that derives from both will ensure that this necessary and multidisciplinary door remains open.