# OF PUBLICS AND SCIENCE

## *HOW PUBLICS ENGAGE WITH BIOTECHNOLOGY AND GENOMICS*

Anne M. Dijkstra

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## *HOW PUBLICS ENGAGE WITH BIOTECHNOLOGY AND GENOMICS*

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# *Introduction*

# Publics and science: Understanding their relationship viewed from the perspective of the public

*In this chapter, first the research project is introduced, followed by a short introduction of two models in the public understanding of science literature that deal with the relationship between the public and science. Then the state of the art of genomics research is briefly described. Next, the scope and research questions of the research project will be presented. Finally, an overview of the thesis will be given.*

## Introduction

In 1957 the exhibition 'Het Atoom' (The Atom) at Schiphol attracted about 750,000 people. The lead act was a bluish glow that showed that the nuclear reactor was actually working. Visitors received an extensive explanation of the working of nuclear energy, detailing lots of possible applications for future household use. The aim of the exhibition was to prepare the Dutch citizen for a new era: the era of nuclear energy. The new technology was accepted with open arms and in 1967 the Queen of the Netherlands opened the first nuclear energy power plant (Geloof in Kernenergie, 2005, 17 May; Verbong & Lagaaij, 2000). It was not until the 1970s, however, that the first protests against nuclear energy were expressed. Soon after, the mood in society changed and public protests rose quickly, culminating in the so-called 'broad societal debates' from 1981 till 1983. The original, but unofficial, plans called for the construction of at least 25 nuclear power stations, but, in fact, only two power stations have ever been built (Geloof in Kernenergie, 2005, 17 May; Verbong, 2000). The technology, while initially being considered promising, has become highly controversial.

In the late 1970s and the 1980s, another new and then highly debated scientific technique, In Vitro Fertilization (IVF), hit the headlines (IVF in Nederland, 2003, 13 May). IVF means that fertilization of the egg cell by the sperm takes place in the laboratory, whereupon the fertilized egg cell is placed back into the patient's uterus. On July 25 1978, the first test-tube baby, called Louise Brown, was born in the UK (Kirjeczyk, 1996, p. 95). A few years later, on May 15 1984, the first Dutch test-tube baby was welcomed in the Rotterdam Hospital Dijkzigt (IVF in Nederland, 2003, 13 May). Although the technique raised many questions about risks and ethics, it never led to broad societal debates like those that nuclear energy triggered. Moreover, risks and ethical issues have never been seriously studied (Kirjeczyk, 1996). The technique has been very successful in terms of numbers of conceptions[1], as, so far, over a million children have been conceived by IVF worldwide (Hall, 2006, 11 July), while Louise Brown gave birth to a son, conceived in the natural way, on 20 December 2006 (BBC News, 2007, 14 January). The technique is largely accepted by the general public.

In 1996, in the UK, the company Zeneca sold small tins of tomato sauce – containing genetically modified (GM) tomatoes, clearly identified as such on the labels – for about 90% of the price of the non-GM equivalent. This low price was arranged as a marketing experiment to let the British public get used to GM products. From 1996 to 1997, 1.6 billion cans of GM tomato sauce were successfully sold in British supermarket chains until public perception about genetically modified foods changed rapidly. However, because of a rapid decline in consumers' trust in GM food – especially due to the BSE (Bovine Spongiform Encephalopathy) or Mad Cow crisis – the product had to be taken off the market immediately (Pritchard & Burch, 2003, p. 93; Zadoks, 2003). Public opinion about the technique has changed dramatically.

The above examples show aspects of the complex relationship between the public and science and technology in general, and between the public and biotechnology in particular. This relationship varies with the particular technologies involved. It changes over time and is in a state of flux at this very moment, as the philosopher Bruno Latour recently said in an interview with the Dutch newspaper *NRC Handelsblad* (Spiering, 2007, 24 February). He argues that the traditional position of science has changed rapidly. The idea that science can change the world has disappeared. Nobody expects that anymore, no more than anybody expects that disseminating scientific information will automatically lead to better-informed citizens. Scientists have fallen from their pedestal. In Latour's view, in the societal debates on science issues, scientists have become agents like any other in the process.

This research project studies the relationship between the public and science, focusing on the role and the perspective of the public. The empirical basis for this research project consists of the developments regarding biotechnology and genomics in the Netherlands,

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[1] The success rate at the level of the individual depends on several factors, e.g., age, and it is therefore difficult to give an exact success rate in percentages. In general, it is acknowledged that the success rate for individuals is low, i.e., the chance that IVF leads to pregnancy in any given woman, is considerably less than 50%.

since the area of biotechnology and genomics is an interesting and conflict-laden area where science and society are intertwined, and thus the public and science meet (Einsiedel, 2000). Genomics, a relatively new word for all modern technology related to gene research, is a so-called promising technology (COGEM, 2004). In this thesis genomics is understood as the research studying the composition of the genome, and the function of genes on the genome (COGEM, 2004).

It is widely understood that genomics cannot be developed without the support of the public. Politicians as well as researchers agree that the introduction of new technologies, like genomics or nanotechnology, requires public acceptance, in particular when it concerns issues of health and food. This is the lesson learned from biotechnology in the 1980s and 1990s (Gaskell & Bauer, 2001). In fact, the public itself demands a role when it comes to the development of science and technology more in general (Leshner, 2005; Te Molder & Gutteling, 2003), and in biotechnology in particular (Koopman, De Jong, Gutteling, & Seydel). It finds itself interested in science and technology, yet considers itself poorly informed. At the same time, studies show that more knowledge of for example biotechnology does not lead to more support for it, but rather to more criticism (Bauer & Gaskell, 2002; Gaskell & Bauer, 2001, 2005; Midden, Hamstra, Gutteling, & Smink, 1998). The question is how to cope with increasingly critical publics in our contemporary society where small risks can have big consequences. Science's credibility and the public's trust are no longer self-evident (Beck, 1992; Giddens, 1990). Science has lost its expert position, and, according to Gibbons (1999), the old social contract between science and society, where science was expected to produce reliable knowledge and to communicate this knowledge to the receiving society, does no longer hold.

### Two conceptual models

In the literature on the public understanding of science, the relationship between the public and science is approached from two conceptual models or paradigms. In the first or 'deficit' model many scientists believe that the tensions between the public and science can be resolved by telling the public exactly how science and technology work. There is a lack of knowledge of science and technology, and education is supposed to solve this problem. The deficit model focuses on educating a passive public in order to close the assumed 'communication gap' between the public and science (e.g., Logan, 2001; Von Grote & Dierkes, 2000). However, this approach led to criticism, since it is not lack of *knowledge*, but rather lack of *trust* that causes difficulties and that explains the difficult relationship between the public and science. Gottweis (2002) argued that other communication formats are called for. The second or 'interactive science' model offers a different perspective of the public; it states that the public plays an active role in its relationship with science (Wynne, 1991, 1992, 1995). Therefore, the ideal solution for the growing gap between science and society seems to be increased public participation (Gibbons, 1999). It is seen by governments as the way to create acceptance and to restore trust in experts (Hagendijk, 2004), and has become their favourite communication instrument.

Both models build on the assumption that improvement of the relationship between the public and science is needed in a democratic society (Einsiedel & Thorne, 1999; Logan, 2001). However, they differ in the way the public and science are perceived. Although these models are often presented as complete opposites of each other, the aim of this thesis is not to emphasize existing differences, but instead to gain more scientific understanding of the relationship between the public and science. This is done especially from the point of view of the public (Felt, 2000; Logan, 2001; Wersig, 2001). The two aforementioned models will be analyzed theoretically, looking in particular at the concepts of the public and science, and then reflection on these concepts will take place in the empirical studies. Like other authors have stated (Einsiedel & Thorne, 1999; Logan, 2001), in this thesis, it will be argued that the two models are in fact not mutually exclusive. Rather, concepts take different positions depending on a range of influencing factors (Hansen, 2005).

### Genomics: State of the art of a new promise

At this moment, genomics is considered to be the driving force behind a great number of developments in all areas of biotechnology (COGEM, 2004). In the strictest sense of the word, biotechnology is simply a technology based on the manipulation of biological entities and/or processes. This use of micro organisms and their products – in particular fermented products with yeast such as wine, beer and sake – goes back several thousands of years (Becker et al., 2007). In Ullman's encyclopaedia of industrial chemistry (Becker et al., 2007, p. 3) biotechnology is described as 'the commercial application of living organisms or their products, which involves the deliberate manipulation of their DNA molecules'. This description refers to laboratory techniques of artificial selection and hybridization mainly developed within the last 20 years. Nowadays, biotechnology is a multidisciplinary technology that has been applied in many industrial branches such as medicine, agriculture, and food science. In the public domain 'biotechnology' is often used to refer to genetic engineering technology.

Genomics can be described as 'the study of an organism's entire genome', including efforts to determine the entire DNA sequence of organisms, fine-scale genetic mapping, and the determination of the functions of genes on the genome *(functional genomics)*(COGEM, 2004). The expression 'genomics' was first introduced in 1987 and became more widely known in the 1990s when the Human Genome Project, meant to determine the sequence of the human genome, started. At the start of the Human Genome Project it was expected that knowledge of the genome would quickly lead to impressive results that could be used in pharmaceutical and other applications. However, nowadays this hope is somewhat diminished. One of the reasons for this is the finding that genomes seem to be more complex than what was previously believed to be the case. In addition, the avalanches of data obtained still have to be analyzed and compared with each other. Furthermore, in reality most of the published sequences are not completely finished sequences. For example, although the complete sequence of the human genome was published in 2005, about 1.5 per cent of the sequence still cannot be analyzed due to technical reasons. Moreover, at the moment only a small part of the total genetic variation is known, since the number of organisms that has been sequenced is rather small (COGEM, 2004).

Genomics, like biotechnology, can be applied to several areas. *Red* genomics concerns medical applications. *Green* genomics is genomics applied to agricultural applications, like for example food genomics. *White* genomics refers to industrial applications (COGEM, 2004). Sometimes, a fourth (but rare) application area is distinguished: the term *blue* genomics is used to describe marine and aquatic applications (Becker et al., 2007).

Recent developments in genomics have led to several new technologies. The technology of *metabolomics* identifies so-called metabolites and thereby measures which reactions take place in a cell, tissue or organism. Other new technologies are for example, *transcriptomics*, which measures the activity of genes and shows which information in the gene is read out; and *proteomics*, which maps which proteins exist in a cell, tissue or organism, and how these proteins change due to external factors. In addition, understanding of genomics is based on the analysis of huge amounts of data, which is the reason why the development of *bio-informatics* is essential (Netherlands Genomics Initiative, 2007). Even more recently, integration of several of the new developments, like bio-informatics, genomics, and nanoscience (the study of objects and organisms at the nano-level), made it possible to change directions, that is, *designing* organisms in stead of *modifying* them. This new branch of technology, called *synthetic biology*, is already capable of synthesizing the complete genome of a virus of which the DNA sequence is known (De Vriend, 2006; De Vriend, Van Est, & Walhout, 2007).

Biotechnology is often contested in society. Some aspects, like medical applications, are appreciated, while others, like food applications, are despised. A well-known example of this negative attitude towards GM foods is the widely accepted phrase ‘Frankenstein food’ introduced by Prince Charles. The negative public reactions towards biotechnology influence perceptions of genomics as well. At this point, the discussion about biotechnology and genomics is left for what it is and the scope and the main research questions in this research project will be addressed. A more detailed account of current developments in - and public perceptions of - biotechnology and genomics, will be given in Chapter 1.

## Scope of the research and research questions

The objective of this research project is to investigate the relationship between the public and science from the perspective of the public, by studying the relationship between the public and genomics, in other words, how publics understand genomics and their own and others’ roles regarding genomics. The second objective is to contribute to theory formation with respect to the public understanding of science, since the analysis is based on concepts derived from the two dominant models in this field. The third and final objective of this research project is to produce practical recommendations in order to stimulate science communication about genomics.

The main topic in this thesis is the question how the relationship between the public and science can be understood from the perspective of the public. In line with what other authors have argued, in this thesis the public at large is not considered a homogeneous group, but rather a heterogeneous compilation of different publics (e.g. Dewey, 1954; Einsiedel, 2000; Neidhardt, 1993). Thus, the main research question can be formulated as follows:

*RQ:* *How can the relationship between publics and science be understood?*

To study this relationship, three empirical studies were conducted. In these empirical studies the focus was on the relationship between the public and biotechnology and between the public and genomics more specifically. Therefore, from the general question about the public’s relationship with science, three more specific research questions were derived, each focusing on certain aspects of public’s (or publics’) relation with science.

*RQ1:* *Which roles have publics played in Dutch biotechnology debates?*
*RQ2:* *Which considerations do publics in various roles have regarding (communication aspects of) genomics?*

*RQ3: How do publics, passively or actively participating in gene research, differ in their relationship with genomics?*

From the perspective of the public understanding of science, two models analyze the relationship between public and science. On the one hand, the two models differ in their theoretical conceptualization. On the other hand, most studies based on the models restrict their methods of research: quantitative methods are used in the *deficit model*, as opposed to qualitative methods in the *interactive science model*. Various authors have warned for unnecessary and unhelpful mixing up of theory and method (Sturgis & Allum, 2004). Other authors have argued that a multi-method design, which includes qualitative as well as quantitative methods, leads to a multifaceted picture and thus to a deepened understanding of the public and its relationship with science (Von Grote & Dierkes, 2000). According to them, applying both qualitative and quantitative methods will lead to a broader understanding of the ways publics understand, accept and use science and technology.

## Outline of the thesis

In Chapter 1 the context for this thesis and the empirical studies are presented. Rationales for science communication practice in the Netherlands and elsewhere are described. An overview of the Dutch political and judicial context of biotechnology and genomics is given, complemented by details on the public's perceptions of and attitudes towards science and technology in general, and towards biotechnology and genomics in particular.

In Chapter 2, an overview of the theoretical framework is presented. Developments in the literature on the public understanding of science that have led to the two conceptual models will be described. Relevant notions from other research areas – such as risk communication, health communication, and public participation – that contributed significantly to the conceptualization of the main concepts, are reviewed as well. At the end of this chapter, an analysis of core concepts and their positions within the two models will be presented. In Chapter 3, methodological issues concerning the use of mixed methods will be discussed. The next chapters (Chapters 4, 5 and 6) review the results of three empirical studies.

In Chapter 4, the results of a document analysis are presented in which the roles the general public and science played in five Dutch public debates on biotechnology are analyzed. Chapter 5 presents the results of the analysis of the focus group discussions, by means of which it was investigated how publics in various roles perceive gene research and the communication strategies surrounding this research. In Chapter 6, differences between groups in their participating behaviour in gene research were looked at and compared in a survey. In Chapter 7, the picture that the three studies together give of the public and genomics is presented and conclusions are drawn regarding the significance of these findings for the relationship between the public and science. Finally, the findings are reflected on and theoretical and practical implications of the research project for researchers and politicians are discussed.

## Chapter 1

# Societal developments in science communication, biotechnology and genomics

*In this chapter, a historical sketch will be presented of governmental rationales for science information and communication in the Netherlands from the 1950s onwards, followed by an overview of the societal developments surrounding biotechnology. Furthermore, a description is given of Dutch public attitudes towards science and technology in general, and towards biotechnology and genomics in particular.*

### 1.1 History of governmental efforts in Dutch science information and communication and international developments

Dutch science information[1] followed in the footsteps of Dutch public information. Immediately after World War II, the government was focused on rebuilding Dutch society. In this process, science and technology played a role based on the economic principle that whatever is right for science and technology is also right for society. As a discipline, science information did not really exist, but attention to popularization had been growing, with the aim of acquiring societal support for science and technology. In the mid-1950s, the so-called commission Bender argued that universities should attempt to systematically improve relations with groups in society they depend on and should try to gain public trust (Dalderup, 2000; Stappers, Reijnders, Möller, & Hesp, 1983).[2] A democratic rationale for science information emerged: everyone is entitled to access to knowledge and information; everyone should be able to discuss matters of science and technology. At the end of the 1950s the first science information officials started working at the universities, but, compared to what was happening in other countries, e.g., in the United States, the United Kingdom and France, science information in the Netherlands was still in its infancy (Dalderup 2000; Dijkstra, Seydel, & Gutteling, 2004; Wiedenhof, 1978).

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[1] Science information is used in this thesis as the translation for the Dutch phrase 'wetenschapsvoorlichting'. Although the phrase science education might be a better translation, this phrase is not used to avoid mixing up with the Dutch 'wetenschapseducatie' which refers to a somewhat different research area.

[2] '… het op systematische wijze bevorderen van goede betrekkingen met die groepen in de maatschappij waarvan de universiteit in zekere mate afhankelijk is, en het winnen van vertrouwen' (Dalderup, 2000, p. 172).

Science information received a boost when the first Minister of Research Policy, Boy Trip, took office in 1973. In his report[3] on research policy, he discussed extensively the various backgrounds of both research policy and science information. According to Minister Trip, the pursuit of scholarly work should not take place or be considered separate from its societal context. Consequently, scientists should strive to be in close contact with the actors concerned. He believed that, in this way, the public would be able to develop an opinion about scientific research, and public participation in research could be improved. In 1978, as a result of the report, the Office of Science Information was established,[4] which championed the principle that citizens have the right to know and understand (Stappers et al., 1983).

A few years later, in 1984, a new report, titled *Integration of Science and Technology in Society,*[5] was published by the then Minister Deetman (Ministry of Education, Culture and Science) in which the dissemination of information, the development of public opinion, and social decision making were key themes. At the same time, public debates were going on in society about issues of nuclear energy and the environment. According to Minister Deetman, it was necessary to intensify and diversify the information dissemination efforts since science information would need continuous attention. Seen from this perspective, it became clear that an economic rationale for science information started playing a role. Scientific knowledge and technical knowledge, the latter being mentioned for the first time as well, were considered indispensable for achieving economic progress. In 1986, in order to increase the information dissemination efforts two new organizations were established that were charged with this task: the Foundation for Public Information on Science and Technology (PWT), which replaced the Office of Science Information, and the Netherlands Organization for Technology Assessment (NOTA), which, in 1994, was renamed the Rathenau Institute. The former's task was to inform the general public about science and technology (Wiedenhof, 1995). The latter was commissioned to study societal and ethical aspects of science and technology, to inform policy makers about the results, and to stimulate public debate about new developments.[6]

In 1989, in his last report during his time in office, Minister Deetman advocated the strengthening of public support for science and technology. He considered the democratic approach urgently required, since high-pace developments in science and technology were widening the gap between science and the public. Thus, fostering science literacy,

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[3] Nota Wetenschapsbeleid (Trip, 1975).

[4] Dienst Wetenschapsvoorlichting (Dalderup, 2000).

[5] Integratie van Wetenschap en Techniek in de Samenleving (IWTS) in 1984 published by Minister Deetman from the Ministry of Education, Culture and Science (Deetman, 1984).

[6] The idea of the institute was partly based on the experiences in the US with the Office of Technology Assessment (Tuininga, 2000).

through increasing knowledge, became an important goal of public information campaigns. Several new initiatives, such as the Science & Technology Week, were more and more widely organized. At the same time during the early 1990s, a series of public debates on biotechnology was organized in order to increase public support (Dalderup, 2000; see also Table 1 in this chapter, and Chapter 4 where these debates are analyzed). It was not only for democratic reasons that communication activities were organized. At the same time, there was a growing awareness that science and technology were inherently linked with our culture.

In 1995, Wiedenhof (1995) evaluated the past ten years of science information campaigns. He concluded that the economic drive had become more influential but that democratic and cultural rationales were still playing a role. According to him, this attention to democratic and cultural motives was one of the reasons that science information activities in the Netherlands were doing well, compared to developments abroad (Wiedenhof, 1995). In the following years some changes occurred. More often the government interfered in *science communication* – as science information was called from that moment – and demanded effects. Science communication efforts became more aimed at education and the successor of PWT, called the Foundation for Science and Technology,[7] was discontinued in 2004. Since that time, the economic rationale has become dominant and science communication is more aimed at providing information. The democratic and the cultural motives for science communication were relegated into the background (Dalderup, 2000; Dijkstra, 2007).

In essence, this historical sketch shows that, after the Second World War, in Dutch society, there were three rationales or motives for engaging in science communication. From a democratic perspective, it is important that people are able to discuss about and engage in science and technology. People have the right to know. Most public participation activities are based on this premise. The economic motive emphasizes that, in a democratic society more knowledge and acceptance of science and technology leads to economic benefits for society. Most efforts to popularize science support this view at least in part. To a lesser extent, a third rationale has played a role: the cultural motive that states says that science and technology are inherent parts of society that we cannot do without (Dalderup, 2000).

*Some international developments in science communication*

In the beginning of the 1950s, earlier than was the case in the Netherlands, science information in the UK received increased attention. From the 1980s onwards, the politicization

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[7] Stichting Weten.

of science information – in the footsteps of the public debates on various scientific issues – led to the founding of a commission that was put in charge of the evaluation of past science information efforts. This commission, under leadership of (the later) Sir Walter Bodmer, published its report in 1985. It was this influential report that worried policy makers since it showed concern for the general publics' level of understanding of science (Weldon, 2004; Ziman, 1991). Hereafter, science information activities blossomed widely. However, in 2000 a House of Lords' report expressed concerns about the relationship between society and science. Effectively, the crisis of trust would require a shift towards public engagement in science (House of Lords, 2000; Weldon, 2004).

Like in the UK, in the US there was also much attention for science information early on. In the first place, the Second World War had made it clear that science and technology had influenced the outcomes of the war in a positive way, and science was considered the 'new endless frontier', as Vannevar Bush told President Roosevelt (Hård & Jamison, 2005). In the US and in other countries, new institutions, such as the National Science Foundation, were founded, and at these institutions scientists were expected to take on new roles at the interface between science and society. In the second place, the launching of the Sputnik satellite, sent into space by the Soviets in 1957, left the US in shock. Active encouragement of science and technology was needed. Survey results showed that American attitudes towards science were positive, but that their levels of knowledge were low. From that moment on, it was thought that improving peoples' scientific literacy was required, and that science education in particular could effectuate that (Gregory & Miller, 1998).

## 1.2 Biotechnology in international and Dutch perspective

From its beginning, biotechnology has drawn attention from both society and scientists (see Table 1.1). Since the discovery of the double helix structure of DNA by Watson and Crick in 1953, a debate on biotechnology went underway – especially in Europe – in the context of discussions on other issues such as atomic weapons, nuclear energy, environmental problems and pesticides. Although in 1975, during the Asilomar conference, scientists initially decided on a moratorium after the first successful attempts to transfer genes from one species to another, field trials in the 1980s led to discussions about control and regulation of such experiments as well as about concerns over the products being developed (Zoeteman, Berendsen, & Kuyper, 2005). In the 1980s and 1990s, GM food and crops increasingly became the focus of controversy in Europe, whereas medical applications generally received some public support (Grabner, Hampel, Lindsey, & Torgersen, 2001). In general, the biotechnology debate attracted considerably less attention on the other side of the Atlantic Ocean, in the US and Canada than was the case in Europe

(Gaskell et al., 2001). In 1990, the Human Genome Project started, which resulted in extensive media coverage world-wide. In 1997, Dolly the sheep, together with Monsanto's RoundUp-Ready Soy led to a surge in the debates on biotechnology. Other issues that contributed to these world wide debates, were the Pustzai publication in 1998 and the Monarch butterfly study in 1999 (Grabner et al., 2001). In 2000, a rough blueprint of the human genome was published, and this blueprint was finalized in April 2003. In 2004, the publication of the first cloned human embryo by South Korean researchers received widespread attention, until two years later this turned out to be a hoax.

### *Dutch policies regarding biotechnology*

From 1993 until 2001, five public debates about biotechnology were held in the Netherlands (see Chapter 4). These debates on biotechnology were preceded by a number of rather critical and intense societal debates in the 1970s on issues such as nuclear energy, the environment, microelectronics and recombinant DNA. In these societal debates considerable concern about the socially-responsible use of technology was manifested.

The societal debates influenced Dutch policy in the sense that policy regarding biotechnology has always been two-sided. On the one hand, the Netherlands invested strongly in the development of biotechnology in the 1980s; on the other hand, risks were considered relatively early. As early as in 1981, a committee ('de Brede Commissie') was installed to advise the government on the benefits and the risks of recombinant DNA research. In the 1980s and 1990s, the Dutch attitudes towards modern biotechnology were relatively positive compared to the European average (Gutteling, Midden, Smink, & Meijders, 2001, Midden et al., 1998). For example, after Dolly the sheep was born in 1997 and the RoundUp-Ready Soy was put on the market by Monsanto in the same year, the sudden shift in media coverage that was seen in other European countries did not happen in the Netherlands (Einsiedel et al., 2002). Generally, it is believed that this open attitude towards biotechnology in the Netherlands is influenced by the so-called 'polder model' (Midden et al., 1998). According to this model, the political structure of Dutch society is characterized by a consultative structure that focuses on reaching consensus between government and social partners. In the 1990s, economic success was ascribed to this consensus orientation.

However, in recent years this polder model has been blamed for the opposite, i.e., for economic failure due to indecisiveness. Several factors contributed to this impasse. Since September 2000 economic decline started with the bursting of the internet bubble, two popular Dutch companies (Shell and Albert Heijn) being accused of involvement in stock market fraud, and, in 2002, a – for Dutch standards unprecedented - political assassination of a successful new politician. Together with international developments such as the 9/11 attacks, and the increasing fear of terrorism, the Dutch multicultural society came under fire. This led to a new coalition of parties in power that governed from 2003 till 2006. The parties – the Christian democrats (CDA), the liberals (VVD), and the social democrats (D66) – criticized the polder model for being unable to anticipate the national and international developments described above. In policy making economic prospects were emphasized instead, and consequently, in recent years no organized debates on biotechnology have taken place in the Netherlands. In 2005, the Dutch Consumer and Biotechnology Foundation, an organization that was founded in 1991, in order to actively promote the forming of opinion about biotechnology, was dismantled.

**Table 1.1: Overview of international and Dutch developments in biotechnology**[a]

| Year | International Developments | Dutch Developments |
|---|---|---|
| 1953 | Watson & Crick discover double helix structure of DNA | |
| From the 1970s onwards | | Informal societal debates, e.g., on nuclear energy, environmental issues, and health issues. |
| 1975 | The Asilomar conference decides for a moratorium on rDNA research | |
| 1981-1983 | | Broad societal debate on nuclear energy |
| 1987-1993 | | Several surveys and other studies are conducted to measure perceptions about biotechnology among the Dutch public |
| 1991-1999 | | Committee Biotechnology (Brede Commissie), organized by PWT & NOTA, provides uninvited advice to the government and organizes a broad public information campaign |
| 1990s | First GM Food products for sale | |
| 1990 | Start of the Human Genome Project | Herman the Bull is born with the gene lactoferrin implanted |
| 1993 | | Debate *Transgenic Animals* |
| 1995 | | Debate *Human Genetic Screening* |
| 1996 | BSE crisis in the UK | Debate *Environmental development* |
| 1997 | Labelling directed<br>Cloning of Dolly the sheep<br>Monsanto's RoundUp-Ready Soy put on the market | |
| 1998 | Pusztai publication<br>Approval of Bt maize in Europe | |
| 1998-1999 | | Debate *Clones and Cloning* |
| 1999 | Monarch butterfly study<br>WTO meeting in Seattle | |
| 1999-2000 | | Debate *Xenotransplantation* |
| 2000 | Rough draft of the blueprint of the Human Genome published in *Science*<br>Approval of the Biosecurity Protocol, Montreal<br>Golden rice | |
| 2001 | | Debate *GM food* |
| 2003 | Blueprint of the Human Genome finished | Survey *Public Perception of Genomics* and focus groups |
| 2004 | South Korean scientists isolate stem cells and claim to have cloned human embryos | Trend analysis *Biotechnology* with focus groups |
| 2005 | | |
| 2006 | South Korean study turns out to be a hoax | (Follow-up) Survey *Public Perception of Genomics* |

[a] Sources: Becker et al., 2007; Einsiedel et al., 2002; Grabner et al, 2001; Midden et al., 1998; Ministerie van VWS, 1999; Pin and Gutteling, 2005.

**Table 1.2: Key dates of regulation and legislation in the Netherlands and Europe**[a]

| Year | Establishment of Dutch committees and passing of Dutch legislation | European legislation |
|---|---|---|
| 1979 | Ad Hoc Committee on recombinant DNA | |
| 1981 | Broad DNA Committee, 'Hinderwet'/ Regulation for the protection of humans and the environment | |
| 1989 | Schroten Committee on animal biotechnology | |
| 1990 | VCOGEM (environmental safety) replaces Ad Hoc Committee on recombinant DNA<br>Implementation of the directives 90/219 and 90/220 in the national legislation (Law on Environmentally Harmful Compounds / 'Wet Milieugevaarlijke Stoffen, besluit ggo') | EU directive 90/219/EEG on the use of GMOs<br>EU directive 90/220/EEG on the introduction of GMOs into the environment |
| 1993 | The new law on animal welfare is effective | |
| 1995 | COGEM (Committee Genetic Modification, based on the Law for Environmental Safety) is installed | |
| 1996 | The law on medical testing is passed. It includes a moratorium on hereditary research (Dutch Embryo Act);<br>Schroten Committee becomes the CBD (Committee Biotechnology by Animals) based on the law on animal welfare | |
| 1997 | The national labelling directive (within the existing Food Law) is rejected by the court | EC regulation 97/258/EG on Novel Foods |
| 1998 | GMO Regulation. It includes technical guidelines for activities with GMOs<br>Prenatal gender choice for non-medical reasons is prohibited<br>Conditions under which research using humans is allowed are regulated | The de facto EU 1998 moratorium is effective[b] |
| 1999 | CCMO (Central Committee on Human Research) | |
| 2000 | Regulation in the Food Law on GM flavourings and additives (EU regulation 2000/50) | EU regulation 2000/50 on the labelling of foodstuffs and food ingredients containing additives and flavourings that have been genetically modified or have been produced from GMOs |
| 2001 | | EU directive 2001/18 on the introduction of GMOs in the environment.<br>EU directive 90/220 expired |
| 2003 | | EU regulation 2003/1829 on genetically modified food and feed<br>EU regulation 2003/1830 on the traceability and the labelling of GMOs<br>EU regulation 2003/1946 on transboundary movements of GMOs |
| 2004 | | The de facto EU 1998 moratorium is lifted |
| 2005 | Embryo regulation on stem cells is passed.<br>Animal biotechnology for the purpose of sports and entertainment is prohibited.<br>Societal Covenant Coexistence (self-regulation plants by industry) | |

[a] Sources: Gutteling et al, 2001, p. 231; Midden et al, 1998; Zoeteman et al, 2005.

[b] The EU moratorium on the harvest of GMO crops and products was effective due to stagnation in the admittance policy that was the result of exercised vetoes by the member states. This de facto moratorium was effective until the revision of the EU directive 90/220 in 2004.

In addition, both scientists and industry pushed for strengthening incentives in the biotech sector in order to meet the Lisbon goals for innovation policy of the European Union (COGEM, 2004). However, since 2006 a new coalition of parties (i.e. Christian democrats (CDA), socialists (PvdA) and more religious Christians (Christenunie)) are in power and consensus is once again more strived at.

*Dutch regulation and legislation of biotechnology*

The regulation of biotechnology in the Netherlands is based on the implementation of international and European legislation, and, in particular, on European Union regulation and directives. Table 1.2 provides an overview of the relevant juridical frameworks and the committees that deal with biotechnology issues. Depending on the specific biotechnological application and the involvement of genetically modified organisms (GGOs in Dutch legislation terms), several legal frameworks are involved: frameworks for the evaluation of the safety for human beings and for the environment, product safety, the acceptability of herbicides, intellectual property rights and the protection of employees and animals.

In general, principles regarding policy and legislation concerning biotechnology in the Netherlands are based on the criteria of legitimacy, practicability, sustainability, suitability, quality, safety, transparency and the implementation of the so-called ‘precautionary principle’ (Beleidsnota Biotechnologie, 2000). In 1995, the COGEM (Committee Genetic Modification) was installed to advise the government on genetic modification and to report – both invited and uninvited – on ethical and societal aspects on the technology. In 1996, the CBD (Committee for Animal Biotechnology) was installed. In 1999, when the CCMO (Central Committee Human Research) was installed, the government decided that advice regarding gene therapy would be the responsibility of this committee.

## 1.3 Dutch public (risk) perceptions of and attitudes towards science, technology, biotechnology, and genomics

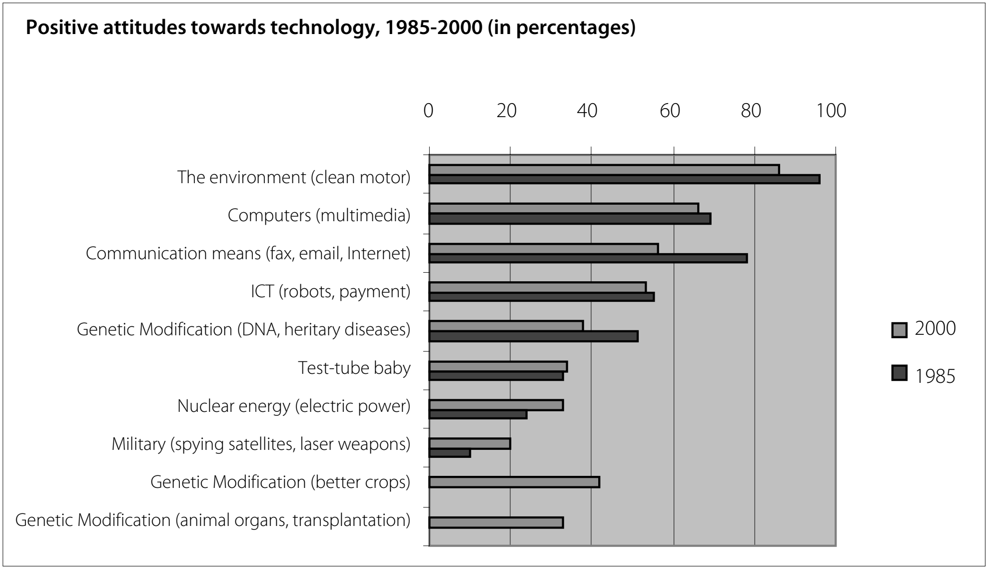
In this section a summary is presented of Dutch public perceptions of and attitudes towards science and technology in general, and biotechnology and genomics in particular. A systematic study of these perceptions and attitudes was carried out in several Eurobarometer surveys (Bauer & Gaskell, 2002; Gaskell, Bauer, Durant, & Allum, 1999; Gaskell & Bauer, 2001). In the Netherlands, general perceptions of and attitudes towards science and technology have not been measured since 2000 (Becker & Van Rooijen, 2001). (Risk) perceptions of and attitudes towards biotechnology have been measured amongst other things, in a monitor study from 1992 to 1996, in surveys in 2001 during the debate on GM food, and in two surveys on genomics in 2002 and 2005 (Heijs & Midden, 1997; Gutteling et al., 2001a; Gutteling et al., 2001b; Hanssen, Gutteling, Lagerwerf, Bartels, & Roeterdink, 2001; Gutteling, Hanssen, Van der Veer, & Seydel, 2006; Stichting Consument en Biotechnologie, 2002; Pin & Gutteling, 2005).

*General attitudes towards science and technology*

In 2000 the Social and Cultural Planning Office (SCP) and the Dutch Organization for Scientific Research (NWO) conducted a survey among 1244 households with 1777 interviews (Becker & Van Rooijen, 2001). Summarized, results showed that science is to a large extent identified with doing research. In the public eye science is trustworthy and prestigious. There is marked optimism about the ability of science to solve today's problems (see Table 3). Between 1985 and 2000, attitudes towards technological innovations became more positive. Only nuclear energy and the use of nuclear material for military purposes were considered more negatively in 2000 than in 1985. The Dutch public evaluated science and technology in more or less the same way. Both are seen as good and beneficial. People that are satisfied with science, also have a positive attitude towards technology. Interest in science and knowledge of science is mainly determined by the respondent's educational level and gender, as well as on having completed a course in technical training or an education in science (Becker & Van Rooijen, 2001).

Results of a more recent Special Eurobarometer survey (Special Eurobarometer 224, 2005) showed that 97% of the Dutch people, the highest rate in the EU, agree that 'science and technology developments will help cure illnesses such as AIDS or cancer'. On the topic that 'science and technology make our lives healthier, easier and more comfortable', 70% of the respondents agreed. And 85% agreed that 'thanks to science and technology, there will be more opportunities for future generations'. Only 39% were of the opinion that 'science's benefits are greater than any harmful effects it may have'. Meanwhile, 31% agreed that 'science and technology will help eliminate poverty and hunger around the world', and 15% agreed that 'science and technology will allow the Earth's natural resources to be inexhaustible'. Finally, only 7% of the respondents, the lowest percentage in the EU, put hope into science and technology 'for sorting out any kind of problem' (Special Eurobarometer 224, 2005). When the Dutch figures are compared with the European average values, it becomes clear that the Dutch are the most optimistic about the possibilities of science and technology to cure diseases such as AIDS and cancer. However, at the same time they are doubtful that 'science and technology could sort out any problem'. Similar patterns were found in Sweden and Denmark (Special Eurobarometer 224, 2005).

**Table 1.3: Attitudes towards technology**[a]



[a] Source: Becker and Van Rooijen, 2001, p. 32.

*Perceptions of and attitudes towards applications of biotechnology*

From 1992 until 1996, Heijs and Midden (1997) conducted four monitor studies on the perceptions, attitudes and influencing factors with regard to biotechnology. The monitor study showed that perceptions and attitudes can vary substantially and that a general attitude towards biotechnological applications is not demonstrable. Emotions appeared to dominate the formation of attitudes. The knowledge tests showed low levels of background knowledge. Awareness of the various applications was fairly consistent throughout the four studies. The Dutch public remained interested and involved in new developments in biotechnology during the study.

In 2001 and 2002, during and shortly after the Dutch public debate on GM food, three surveys examined opinions about the application of gene technology in food products among the general public (Gutteling et al., 2001a; Gutteling et al., 2001b; Gutteling et al., 2006; Hanssen et al., 2001). In 2002 and 2005, respondents were asked for their opinions of genomics, including food and medical applications (Stichting Consument en Biotechnologie, 2002; Pin & Gutteling, 2005).

When exploring interests of the respondents in different areas of research (see Table 1.4), the 2005 genomics survey showed that most respondents (89%) were interested in DNA identification for forensic purposes, followed by diseases and their treatment (86%), and genetic research and heredity (84%). The interest in the latter subject seems to have increased slightly compared to the findings of 2002 (70%). Relatively little interest was found for the subjects of cloning (26%) and genetic modification (38%). An explanation for the low interest in cloning could be that, at the moment the survey was conducted in the Netherlands, hardly any debate on cloning was going on, due to a moratorium proclaimed by the Dutch government. As shown in Table 1.5, at the same time, human cloning was rejected by 97% of the Dutch public.

More generally, when comparing the results of the two public surveys on genomics in 2002 and 2005, few significant differences in time were found. These differences were related to issues such as skills and genes as well as to the relationship between the attitudes towards new developments and religious activity (Pin & Gutteling, 2005).

**Table 1.4: Interest in biotechnology**[a]

| **Interest in areas of gene research and genomics:** [b] | **Percentage interested or very interested**[c] | |
|---|---|---|
| | *2002* | *2005* |
| Diseases / treatment | 86 | 86 |
| Cloning | 18 | 26 |
| Genetic modification | 25 | 38 |
| Genetic research and heredity | 70 | 84 |
| DNA identification for forensic purposes | | 89 |
| Gene food technology | | 52 |

[a] Source: Pin and Gutteling, 2005.

[b] 'In which of the following scientific and technological developments are you interested?'

[c] Results are not comparable due to the use of different measurement scales in the two surveys: in 2002 a 5-point scale was employed, while 2005 a 4-point scale was used.

**Table 1.5: Attitudes towards the applicability of genetic research**[a]

| **The extent to which people are positive or negative towards:** [b] | **Percentage (very) positive** | **Percentage (very) negative** |
|---|---|---|
| Mapping the complete human genome (DNA) to prevent diseases | 82 | 5 |
| In 5 years time: the use of gene technology for the production of food to help prevent intestine cancer | 71 | 12 |
| Modifying rice to make it more suitable for dry areas | 62 | 21 |
| In 5 years time: the storage of the DNA-code of all Dutch people in a biobank | 60 | 27 |
| Genetic modification of plants for food production for people with allergic reactions to food | 55 | 22 |
| Genetic modification of plants to reduce environmental impact | 41 | 34 |
| The use of tissues from embryo's for research of serious diseases | 45 | 31 |
| The use of gene technology for simplifying food production | 23 | 51 |
| Genetically changing animals for world food production | 12 | 70 |
| In 5 years time: an obligatory genetic test for every person that wants to effect an insurance | 8 | 82 |
| In 15 years time: cloning of human beings | 1 | 97 |

[a] Source: Pin and Gutteling, 2005.

[b] To which extent are you positive or negative towards…?

### *Perceptions of and attitudes towards food applications*

Perceptions of and attitudes towards GM food among the Dutch public have been negative, but not as negative as the EU average. Results of the surveys held during the GM food debate in 2002 showed that in this period the familiarity with GM food increased, while personal interest in GM food decreased slightly. In these surveys, 59% of the respondents declared to be more or less concerned with GM technologies and GM food. More people were opposed to GM food than were in favour of it (24% versus 18%), and the percentage of respondents in favour of GM food had grown from 38% in November 2001, to 48% in February 2002. At the same time, these surveys showed a clear disagreement in opinions among the Dutch public. The survey results indicate that the public held three actors responsible for the development of GM food products: the government, scientists, and industry. The respondents emphasized the role of the government to be more important, but government should not be the only actor. And, in general, respondents regarded the level of information available as inadequate (Hanssen et al., 2001; Gutteling et al., 2006).

With regard to food applications, the majority of the respondents indicated to have a negative attitude towards 'the use of gene technology for simplifying food production' (51% negative), 'genetically changing animals for world food production' (70%), while a majority of 62% favoured modifying rice for dry areas (see Table 1.5). Furthermore, in the 2002 genomics survey respondents were asked to give spontaneous answers to the question regarding the disadvantages of gene research related to plants and animals. Answers referring to 'nature', 'animals should not be disturbed', 'monocultures will arise', or 'less diversity' were mentioned by 34% of the respondents (Pin & Gutteling, 2005; Stichting Consument en Biotechnologie, 2002).

Dutch attitudes towards GM food applications have fluctuated over time. The latest Eurobarometer 64.3 reported that 25% of the Dutch citizens supported GM food, while 27% of the Europeans did so (Gaskell et al., 2006). A comparison of the levels of support in previous Eurobarometers studies showed that the Dutch deviated from the European trend. In most EU countries support declined between 1996 and 1999, then increased between 1999 and 2002, and again showed a decline in 2005. In contrast, the Dutch data showed high levels of support that dropped consistently between 1996 (78%), 1999 (75%), 2002 (65%) and 2005 (48%).

### *Perceptions of and attitudes towards medical applications*

The findings above were examined in relation to the findings regarding medical applications. In general, Dutch attitudes towards medical applications have been more positive than attitudes towards food applications. In the 2005 genomics survey, the majority of the respondents positively evaluated the following medical developments: 'mapping DNA to prevent diseases' (82%) and 'use of gene technology against intestinal cancer' (71%). Negative attitudes, on the other hand, were registered with respect to 'obligatory genetic tests for insurance purposes' (82%), and 'cloning of humans', with almost all respondents (97%) rejecting human cloning (see Table 1.5). When, in the 2002 genomics survey, respondents were asked to give spontaneous answers to the question regarding the disadvantages of gene research and heredity in relation to humans, responses such as 'fear for the unnatural excesses', 'imbalance', 'super people', 'super race', 'selection', or 'cloning' were mentioned by 37% of the respondents (Pin & Gutteling, 2005; Stichting Consument en Biotechnologie, 2002).

Similar responses were given in the 2005 genomics survey when respondents were asked to express the disadvantages of gene research and heredity in general. Spontaneously, 25% of the respondents answered that 'it is not good to intervene too much in human nature' (25%) and one 'can not yet oversee the impact, the unknown consequences for nature and people, and the uncontrollable process' (24%). Attitudes did not differ much from the average European average. According to the latest Eurobarometer report on biotechnology, 45% of the Dutch respondents supported gene-therapy compared to 50% of the Europeans supporting gene-therapy (Gaskell et al., 2006).

In general, it is clear that medical applications of biotechnology and genomics receive more support than GM food applications do. Figures of the latest Eurobarometer survey on biotechnology show that Europeans, including the Dutch, supported the development of nanotechnology, pharmacogenetics and gene therapy (Gaskell et al., 2006). These three applications are perceived as useful and morally accepted. These findings stand in contrast to the degree of support for GM food. GM food is widely seen as not useful, as morally unacceptable and as a risk for society (Gaskell et al., 2006). In the Dutch context, the following factors influenced public attitudes towards genetic engineering: regular visitors of a church, mosque or temple (24%) are significantly less positive about developments in genetic research, genetic modification and genomics than the average Dutch citizen (Pin & Gutteling, 2005). No significant differences were found between respondents from the most urban part of the Netherlands (the 'Randstad') and those living elsewhere, for both food and medical applications.

From the above, two conclusions can be drawn that are relevant for the empirical studies in this thesis. Firstly, although democratic and cultural rationales still play a role, currently Dutch science communication is strongly inspired by an economic motive that fosters knowledge and acceptance of science and technology. Secondly, the Dutch are the most optimistic within Europe about the possibilities of science and technology, but, at the same time, they are critical about science and technology. This dualistic attitude is reflected in

Dutch attitudes towards biotechnology and genomics, where people indicated to be interested in applications of both food and medical genomics, but at the same time showed negative attitudes towards food applications, while supported several medical applications.

In the following chapter the theoretical framework for the empirical studies will be provided. Core concepts in the two main models from public understanding of science literature and the differences in the conceptualizations of both models will be analyzed and discussed.

## Chapter 2

# The relationship between publics and science

## A theoretical analysis

*In this chapter theoretical notions concerning the relationship between publics and science are analyzed. Two models from the literature on the public understanding of science*[1] *literature are discussed. Core concepts from the models are considered, in particular the way the public is conceptualized, and how scientific knowledge, information and communication, and trust are regarded. Finally, a provisional analysis of the concepts is presented.*

### 2.1 The public and science: What about it?

Public understanding of science is a research area that studies the relationship between public and science. Theoretical notions from this research area are a starting point for this thesis. In this thesis these notions have been enriched with those from other areas such as risk communication, health communication, and public participation, since knowledge derived from common developments might "accelerate the pace of research" in the public understanding of science field (Logan, 2001, p. 136).

In this chapter a more theoretical understanding of the relationship between the public and science is strived after. Additionally, this understanding provides the basis for the empirical studies conducted in this thesis. The next section (2.2) starts with a review of current theoretical developments in public understanding of science research. Two models guide conceptual ideas in this area. Thereupon, a comparison of differences attributed to similar concepts is given (2.3). Finally, a provisional analysis of the core concepts will be presented (2.4).

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[1] I am aware of the connotations of the phrase 'public understanding of science' has. Originally this was the way the research first was called; hence this label is clearly linked with the deficit model. In this thesis the phrase 'public understanding of science' will be used as a convenient shorthand. However, this does not mean that I regard the field exclusively from the perspective of the deficit model. Neither do I regard it exclusively from that of the interactive science model. Another phrase commonly used to refer to the field is 'science communication', and some authors consider it as more appropriate. In this thesis, this phrase is not used to refer to the research area as such, but to the *activity* of communicating about science.

## 2.2 How publics understand: two conceptual models

In 1991, the international research community's increasing attention for science and the public led to the launching of a new journal, *Public Understanding of Science,* for specialists in this area of study. In the first issue, J.D. Miller (1992, p. 23) remarked: "Over the last three decades, the study of the public understanding of science and technology has become a visible and recognizable area of scholarship." J.D. Miller proposed quantitative and statistical studies to measure public attitudes and behaviour related to scientific issues. However, in the same issue, Wynne (1992), the person who contributed significantly to the development of the research area, expressed his criticism. According to Wynne, too often problems in public understanding of science reflected problems of the dominant approach to science and the public, which are embedded in political issues (Wynne, 1992). Immediately, two opposing views on public understanding of science research emerged, later called the 'deficit model' and the 'interactive science model' respectively, each with its own preferred research methodology (Logan, 2001; Von Grote & Dierkes, 2000; Wynne, 1995).

The first studies conducted in public understanding of science research predominantly used a survey methodology (Logan, 2001; Von Grote & Dierkes, 2000). The most influential were US national survey studies that were conducted from 1957 onwards, and that have been standardized in 1972 (J.D. Miller, 1983, 1992, 1993; S. Miller, 2001; Von Grote & Dierkes, 2000). The first Eurobarometer survey that investigated public attitudes towards science in Europe dates back to 1977. Then, it took until 1989 and 1992 respectively, for subsequent surveys to be carried out. In these surveys, the same way of questioning designed by J.D. Miller was adopted (Von Grote & Dierkes, 2000).

The original US research assumed a basic level of scientific knowledge among the public, together with a vocabulary of scientific concepts and a positive attitude towards science and technology required for a person to be able to participate effectively in a democratic society. Scientific literacy contributes to these two dimensions and, therefore, the popularization of scientific knowledge is essential (Hanssen, Dijkstra, Roeterdink, & Stappers, 2003; J.D. Miller, 1983; Von Grote & Dierkes, 2000). In 1983, J.D. Miller expanded the original conception of scientific literacy and added a third element: the social influence of science and technology on society or, in other words, the consciousness that science and technology influence society and peoples' political choices (J.D. Miller, 1983; Von Grote & Dierkes, 2000). This third condition connected attitudes towards science and technology to understanding and consciousness. This way of thinking strongly emphasized the cognitive level, while non-cognitive aspects, such as normative and emotional aspects, did not play a role (J.D. Miller, 1983, 1993; Von Grote & Dierkes, 2000). The approach became known as the ‘deficit model’[2] (Hanssen et al., 2003; Von Grote & Dierkes, 2000). Below, characteristics and limitations of this model will be discussed, followed by a discussion of characteristics and limitations of the second model, the ‘interactive science model’.

### *2.2.1 Characteristics and limitations of the deficit model*

Researchers in the area of public understanding of science who support the deficit model explained public understanding mainly from a pedagogical perspective (Logan, 2001). In this model it is assumed that scientific knowledge is required for citizens in order to function well in modern societies. A deficit of scientific and technological knowledge leads to a reduced capability of citizens to participate in a democratic society, it affects personal efficacy, and negatively influences the economy. Therefore, improving people’s knowledge is valued as a societal good and is, hence, required. Lack of this knowledge is considered a deficit (Einsiedel, 2000; Einsiedel & Thorne, 1999; Hanssen et al., 2003).

In the deficit model, science is regarded as a fixed body of knowledge, and knowledge is thought to find its way in a linear, persuasive communication process, from the sender (the scientist) to the passive receiver (the public), sometimes with the help of intermediaries such as science journalists, and science information officers (Einsiedel, 2000; Einsiedel & Thorne, 1999; Hanssen et al., 2003).

Scientists and public are seen as located at two opposite poles of the spectrum, with scientists having the primary claim to expert knowledge. Knowledge is considered to be the result of sound science and verifiable facts, and more knowledge is supposed to lead to a better understanding of science, and, hence, to a more positive attitude towards it. In short, scientific literacy, by means of popularizing, is assumed to contribute to more knowledge. Research based on the deficit model focuses on sources of news, reporting, media channels and the public as passive receivers of information, and its methodology mostly consists of survey studies (Einsiedel, 2000; Hanssen et al., 2003; Logan, 2001; Von Grote & Dierkes, 2000; Weigold, 2001).

In the field of risk communication the same view is known as the ‘technical view’, as opposed to the ‘democratic view’ (Fiorino, 1989; Rowan, 1994). In this technical, or technocratic, view, a knowledge deficit of the public is a problem that may be alleviated by providing (more) objective information. This view is based on the premise that the public wants accurate information and scientific expertise, since scientists themselves base their opinions on accurate information as well (Rowan, 1994). In this view, risk communication

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[2] It is also known as traditional model, deficiency model (Weigold, 1999), cognitive deficit model (Einsiedel, 2000), technical view (Rowan, 1994), and science literacy model (Logan, 2001).

is regarded as technical, quantitative, or statistical information on risks (Gutteling & Wiegman, 1996). The expert-to-lay transfer of information is seen as a one-way process. Experts, i.e., scientists, use informing and persuading as communication goals in order to achieve information transmission. In this view, experts see the public as unable to handle complex risk information. The public is believed to lack an adequate understanding of technical information, which should be the basis for decisions. Experts are believed to make more rational decisions (Fiorino, 1990). This technical orientation explains why the public's opinion is often being ignored (Fiorino, 1989; 1990; Gutteling & Wiegman, 1996; Rowan, 1994). According to the traditional view, rational and factual information will increase the public's knowledge and opinions will change accordingly (Gutteling & Seydel, 2000; Rowan, 1994).

Logan (2001) stated that, at the same time, a similar conceptual evolution took place in the area of health communication and in the public understanding of science domain. The conventional approach in health communication, called the rational cognitive approach, stressed prevention of diseases. This approach assumed that more knowledge leads to changes in attitude and behaviour. Educational and preventive programs underline the improvement of knowledge and understanding of health issues (Jacobs, Braakman, & Houweling, 2005; Logan & Longo, 1999).

However, in public understanding of science, the deficit approach has already been criticized almost three decades ago. Trachtman (1981), for example, doubted the notion that for a democratic society to function properly, an informed public is a prerequisite. He wondered why so much science information or science communication would be required. According to him, there seem three bases underlying the assumption that an informed public is needed. First, knowledge is simply a good thing in itself. Second, people will be able to make more intelligent personal consumer decisions if they have more knowledge about science and technology. And, third, a democratic society depends upon the existence of enlightened citizens. The political and social behaviour of these citizens in voting, in influencing both elective and appointed officials and in engaging in political and social activism, will be more constructive for society if it is informed by scientific understanding. Trachtman (1981, p. 10) countered that these claims cannot be proven.

Trachtman (1981) agreed that knowledge is a good thing, but thought that more convincing arguments would be needed when large sums of public money are spent on efforts to inform the public. Further, he argued that is has not been proven that consumer decisions will improve one the public is scientifically informed. According to him, it is doubtful that scientists will make more intelligent choices in everyday lives than non-scientists. He even argued that a person with more information would be more likely to make a *worse* decision, due to contradictory or vague information. For example, from political subjects it is known that more information leads to a reduction in clarity. According to Trachtman (1981), it is difficult for an individual to get a clear point of view about an issue and even knowledge institutes have difficulties reaching consensus about issues. In the end, decisions are assessed in a political, economic, social and ethical context. The public is able to make informed decisions just as well based on scientific as on non-scientific knowledge. Much emotionally-embedded information can easily be understood without any scientific knowledge. Thus, Trachtman (1981) argued that it was time to revise the existing assumptions about public understanding of science activities.

In the 1990s, other findings from studies performed as a result of the so-called Bodmer-report[3] showed that science is not something given or something that can really be understood (Silverstone, 1991; Wynne, 1991; Ziman, 1991). Ziman (1991), who contributed to the studies, pointed out that:

> … it is a reminder that what counts as science is sometimes defined very differently by different people – or even by the same people under different circumstances […]. In other words, "science" is not a sharply defined and special type of knowledge, which only starts to be misrepresented and misunderstood outside well-defined boundaries by people who simply do not know any better (p. 100).

That is why he argued that the deficit approach, with its focus on scientific literacy, does not provide an adequate analytical framework for many of the findings derived from their studies. Ziman (1991) suggested that other factors in the analytical framework need to be taken into account, such as the idea that people do not shape their opinions based on a clear image of science. What people remember is based on various images they encounter in the media and elsewhere. Further, use of formal scientific knowledge depends on the specific situation and on what is 'en vogue' at a particular moment of time. Hence, knowledge is part of a complex and varied response. And, people do not accept scientific knowledge unconditionally. The credibility of sources depends on its perceived interests in a certain context. Finally, public conflicts between scientists downgrade scientific knowledge, while Ziman (1991) argued that discussions help people to combine that knowledge with other types of knowledge and help incorporate discrepancies and form their own opinion.

Furthermore, the so-called *Bodmer research* provided some insights in the way people use science. The first of the insights Silverstone (1991) discussed is that science has many faces. Mass media are often criticized for not telling the complete truth or right facts, a challenge shared with other media such as museums. The second insight is that

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[3] In 1985, the Royal Societies' report, titled *The Public Understanding of Science* (also known as the *Bodmer Report*) was published. This report is widely held to be the birth of the Public Understanding of Science movement in Britain. The report led to an increase in dissemination activities by scientists (See also chapter 2).

“science is never communicated in a vacuum” (Silverstone, 1991, p. 108). All kinds of factors, like social knowledge and political surroundings, influence science. Thirdly, science is not only (re)constructed by the senders, but also by the receivers. For example, social reinforcement plays a role in the construction of meaning. And formal knowledge of science is used, but in an unpredictable and complex way. Finally, constraints, including political and economical constraints, play a role in the communication process as well (Silverstone, 1991).

In addition to the critique mentioned, Wynne (1991), who also contributed to the studies, reported an ambiguous concept of scientific knowledge. Several different meanings of science appear to exist among the general public, which he called “scientific *understandings* of science” (p. 114). Scientific knowledge cannot be seen without other types of knowledge, such as organizational knowledge or social knowledge. And, when scientists and lay people meet, this is more likely to involve an interactive process than a one-way communication process. Wynne (1991) concluded:

> Thus, the main insight is here that public uptake (or not) of science is not based upon intellectual capability as much as social-institutional factors have to do with social access, trust, and negotiation as opposed to imposed authority. When these motivational factors are positive, people show a remarkable capability to assimilate and use science or other knowledge derived (inter alia) from science (p. 116).

Further critique of the deficit approach was espoused by Von Grote and Dierkes (2000), and focused on the importance given to the measurement of scientific (il)literacy. Furthermore, these authors objected the ease with which general conclusions were drawn from findings about the relationship between science en the public, while those generalizations neglected actual experiences of the public with science. In addition, the conception of the public as one single object does not do justice to the differences that exist between groups of people. The authors proposed to broaden the research, by shifting its focus from the cognitive dimension of knowledge to a more encompassing conception of the way the public understands, accepts and uses science and technology. Thus, the concept of understanding was extended. Additionally, Von Grote and Dierkes (2000) held the opinion that much research originates from political motives. However, they did not deny that the general publics’ knowledge about science and technology is rather limited and that great efforts are made to popularize science and technology.

In the field of risk communication, the main critique on the technocratic view concerns the basic assumptions about the public, i.e., that the public is able to use the same rational style of argumentation and perceives risks the same way as experts do, and that risks are apolitical (cf. Cvetkovich, Vlek & Earle, 1989). Hence, the public is to be blamed when communication efforts fail. However, in reality the public does not react the same way as experts do (Cvetkovich et al., 1989; Fessenden-Raden, Fitchen & Heath, 1987; Gutteling & Seydel, 2000, Slovic, 1987). According to Fessenden-Raden et al. (1987), this way of argumentation could in the long run lead to the public's conviction that experts do not want to take the effort to communicate the risk issues involved in an understandable way and that they ignore the public's view. In turn, this conviction influences people's trust in sources in a negative way. As is the case in public understanding of science research, a lack of public's trust in sources of risk information has also been observed in risk communication research. Information, or knowledge, coming from these sources can even be perceived by the public as less true (Fessenden-Raden et al, 1997; Gutteling & Seydel, 2000).

In health communication, the predominantly unidirectional approach has been criticized by the so-called New Health Promotion, since the rational cognitive approach created a passive audience in stead of active people taking responsibility for their own health (Jacobs et al., 2005). That is why consumer resistance developed and why there was an interest in an alternative model (Logan & Longo, 1999, p. 81). In Table 2.1 the characteristics and limitations of the deficit model are summarized.

**Table 2.1: Characteristics and limitations of the deficit model**

| | **Characteristics** |
|---|---|
| *Basic assumptions* | A deficit of public's knowledge to be solved |
| | 'General' scientific literacy is required |
| | Factual knowledge improves the perception of the public |
| *Role public* | Passive receiver, to be educated |
| | The public needs to be persuaded by scientists |
| *Science and public (relationship role scientist versus role public)* | Scientists are experts, and stand opposite of lay people |
| | The public perceives risks the same way experts do; they rely on experts |
| *Information and communication* | A linear, top-down process |
| | A one-way process of informing and persuasion, transmission |
| *Scientific knowledge* | Scientific knowledge is fixed and certain |
| | The public lacks scientific knowledge |
| | Accurate information or knowledge, scientific expertise |
| *Trust* | A focus on knowledge |
| | A one-dimensional construct, not of concern |
| | **Limitations** |
| | The need for an informed public is questioned |
| | There is no proof that an informed public makes better decisions |
| | The political, economic, social and ethical context is not taken into account |
| | Scientific knowledge is not considered a special type of knowledge |
| | Scientific knowledge and scientific literacy are overemphasized |
| | The experience of the public is neglected in generalizations |
| | Not a lack of knowledge, but a lack of trust is the key issue |

### *2.2.2 Characteristics and limitations of the interactive science model*

Other researchers, e.g., Einsiedel and Thorne (1999) and Logan (2001), shared the critique on the deficit model, and have elaborated further on the two approaches that are used to investigate public's understanding of science. In the second approach, called the interactive science model[4], uncertainties are given more prominent attention, and science is not seen as dissociated from its social and institutional contexts. Instead of a linear and top-down communication process, the communication is conceived as a ritual, two-way process where social factors, cultural context and other elements have their place (Hanssen et al., 2003; Logan, 2001). Knowledge consists of more than just scientific facts, thus trust and credibility become important concepts. Emphasis is placed upon improving the communication between various actors by means of dialogue with and participation of the public.

In the field of risk communication, in reaction to the technocratic view, the democratic view was advocated, which, as is the case for the area of public understanding of science, emphasized public participation in the communication process. From the 1980s onwards, the democratic view fostered maximum involvement and influence of citizens in the decision-making process. Now, the *receivers* are the leading actor rather than the senders. And it is clear that risk perception by members of the public differs from that of the experts. Persuasion as communication strategy is rejected since communication should be aimed at mutual understanding and not at exercising authority. In this view an equal relationship is strived at, with open, two-way communication (Rowan, 1994). Consumer advisory panels are examples of this type of communication meant to stimulate mutual understanding (cf. Gurabardhi, 2005).

In the field of health communication, an emphasis is seen that is similar to that in the areas of public understanding of science and risk communication. In the New Health Promotion, dialogue with people and supporting or coaching them to gain control of and influence on their health and related issues was highlighted. Health promotion appreciated and encouraged the contribution of others (Roberts, 1999). Communication efforts started from the bottom-up, through participative mechanisms and will, in the end, lead to empowerment (Jacobs et al., 2005).

However, not much research has been done to give the premises of the interactive science model a scientific basis (Einsiedel, 2000; Von Grote & Dierkes, 2000). In addition, the democratic view in risk communication has been criticized for placing too much emphasis on ensuring that a fair process is adhered too, and too little on the knowledge of the public. This view assumes that there are no power differences between the parties involved, i.e., that a fair process equals a fair product. Additionally, persuasion as communication goal is not deemed allowable while, according to Rowan (1994), an ideal communication process encourages participants to pursue all communication goals such as self-

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[4] This model is also known under the following labels: democratic model, context model (Weigold, 1999); democratic view (Rowan, 1994); constructivist tradition (Einsiedel, 2000).

expression, listening, informing, entertaining, negotiating and persuading. And still, it is not exactly clear how participative mechanisms (which will be elaborated on in the next section) may involve the public in science and technology. The public demands a role in decisions about science issues, but does not participate on a large scale in practice (Gottweis, 2002; Gutteling, 2001; Gutteling, 2002; Leshner, 2005; Te Molder & Gutteling, 2002). A summary of the characteristics and limitations of the interactive science model is presented in Table 2.2.

When identifying underlying rationales for public understanding of science efforts, it can be concluded that in the deficit model the idea that more knowledge leads to improvements in understanding and acceptance is founded on the technocratic ideal of the 'makeable' society. In this view, the urge for knowledge serves as the guiding principle for economic progress. Although a democratic motive plays a certain role, the economic rationale prevails. In the interactive science model, the democratic rationale, aimed at engagement and participation, plays a more dominant role.

**Table 2.2: Characteristics and limitations of the interactive science model**

| | **Characteristics** |
|---|---|
| *Basic assumptions* | The public is knowledgeable if interested<br>Scientific literacy depends on interests in subjects<br>Political fairness of the situation influences (risk) perception of people |
| *Role public* | An active public, to be involved<br>The public as participant, an empowered public |
| *Science and public (relationship role scientist versus role public)* | Scientists are experts; lay people may be experts<br>The (risk) perception of the public differs from that of experts<br>Social and cultural processes determine risk perception of the public<br>Scientists become supporters or coaches |
| *Information and communication* | An interactive process of translation and negotiation<br>Two-way, multi-way, mutual understanding through dialogue |
| *Scientific knowledge* | Scientific knowledge is surrounded by uncertainty,<br>There are different kinds of knowledge<br>All parties have some knowledge or expertise |
| *Trust* | The necessity of trust and credibility replaces the focus on knowledge<br>Trust is a complex issue<br>There is often a lack of trust<br>Creating trust is a part of the communication process |
| | **Limitations** |
| | Not much empirical research has yet been conducted<br>The emphasis is on a fair process rather than on knowledge of the public<br>The model assumes equal power between scientists and the public<br>Persuasion or one-way communication is rejected<br>In practice, there is no large-scale participation of the public |

### 2.2.3 *Public participation based on a democratic rationale*

In the preceding section, it has been demonstrated that in public understanding of science, risk communication and health communication studies, democratic ('interactive science') models were developed that assigned a more prominent role to public participation. The literature on public participation can be traced back to that in fields such as science and technology studies, and the social sciences, in particular political science. Therefore, it is not a coherent set of theoretical or methodological approaches, but rather a spectrum of ideas on how to manage the relationship between science and technology, on the one hand, and society, on the other (Hansen, 2005). Much of the literature on public participation has taken the premises of the interactive model as a given. In order to improve the understanding of the publics' role in public participation, and of the way this public would like to participate in science issues, next, different elements of public participation will be discussed.

In the past few decades, public participation, or 'citizen participation', has been in the spotlight because of its democratic rationale, i.e., the position that the public should be able, and should be encouraged, to deliberate and decide on new scientific and technological developments. Pidgeon (1998) argued that the idea that the public needs a say in risk issues is based on the citizen's democratic right. Fiorino (1990) mentioned this 'democratic argument' as well. According to him, other arguments for promoting public participation are involved, namely that "lay judgments of risks are as sound [as], or more so than those of experts" (p.227). In other words, it brings about better decisions, and, hence, he argued that public participation makes risk decisions more legitimate (Fiorino, 1990). Politicians tend to view public participation as a way to get public support for new technological developments. But citizens themselves, too, through their critical reflection on scientific and technological developments, demanded opportunities to comment on these developments by means of participation in them (cf. Beck, 1992; Fiorino, 1990; Giddens, 1990; Joss & Durant, 1995; Pidgeon, 1998).

Citizen participation enlarges involvement in new developments and at the same time it can enhance citizens' trust in institutions. In health communication, the new approach creates opportunities for dialogue and deliberation, with the health communicator no longer speaking as an expert, but instead holding a position equal to that of the public, in the role of guide, coach or advocate (Jacobs et al., 2005). In a more general sense, public participation reflects an urge for more democracy; it is about involving the public, and letting the public discuss and decide about scientific and technological developments.

Public participation has been a concept that attracted wide political interest for issues like the environment and health, and risk (Rowe & Frewer, 2005; Wilsdon & Willis, 2004). For example, in the UK, the idea of public participation through the idea of upstream engagement is favoured by politicians. Reasons for this support came from the many food scandals in recent years, the BSE crisis, and the experiences with foot-and-mouth disease. The scandals severely affected the public's level of trust in science and the government (Wilsdon & Willis, 2004). In addition, the European Commission underlined the interactive model in its call for public participation, citizenship and a new partnership for science and society (European Commission, 2001, 2002). Thus, the issue of how to handle critical citizens has been the focus for politicians, and public participation is seen as a solution that could lead to increased public trust in expertise (Hagendijk, 2003). Or, as Hansen (2005, p. 49) put it, pleas for increased public involvement in the government of science and technology were aimed at establishing 'better' decision making through procedures that could democratize technology, mitigate controversy and (re)create public trust in expertise.

For the purpose of this thesis, with regard to public participation, three issues will be addressed. Firstly, conceptually, participation is closely connected to the concept of empowerment. Participation is one of the strategies for enhancing empowerment; it is a prerequisite for empowerment and it is an element of psychological (individual) and community empowerment (Jacobs et al., 2005; Zimmerman, 2000). Both concepts are closely related to other concepts like trust and knowledge, and to the way communication and risks are regarded. According to Zimmerman (2000), "empowering processes at the individual level of analysis include experiences to exert control by participation in decision making or problem solving in one's immediate environment. This may be achieved through participation in community organizations or activities…" (p. 47). He considered participation as one of the critical aspects of the multilevel construct that empowerment is (Zimmerman, 2000). And, public participation in decision making has been a way to gain control at the individual, psychological level of empowerment (Zimmerman, 2000; see also Gurabardhi, 2005).

Secondly, public participation may be considered as a continuous scale where the *level of participation* varies with the level of public involvement and public consultation in decision making. Early on, Arnstein (1969, p. 217) described levels of participation in her often used 'ladder of citizens' participation' (see Table 2.3). Many of the later models can be traced back to this ladder (Jacobs et al., 2005). In Arnstein's view the ladder represented a continuous scale ranging from a situation where experts are in full control of all aspects of decision making (as in the deficit model of public understanding of science) to a situation where the public holds this position of full control (advocated by the interactive science model).

Each rung of the ladder corresponded to the degree of power citizens have in determining the end product. At the bottom level, two rungs, *1) Manipulation* and *2) Therapy,* describe 'levels of non-participation'. In these rungs participants do not actually participate, but the decision makers' objective is to educate or cure the participating member of the public. The next three rungs described what Arnstein (1969) called 'levels of tokenism': *3) Informing, 4) Consultation* and *5) Placation.* Informing is aimed at one-way communication from experts or decision makers to the public, while, at the level of consultation, participating citizens provide experts with relevant information on the issues involved. In the process of consultation, citizens may be heard, but they lack the power to make sure that something is done with the views they express. There is no follow-up on the activity of providing information. The rung of placation is restricted to the situation in which participants can give advice, but the decision makers still can choose whether or not to take the advice into account. The three top rungs, *6) Partnership, 7) Delegated power* and *8) Citizen Control,* Arnstein (1969) labelled 'levels of citizen power'. The higher on the ladder, the more power participants gain to decide about the issues involved. At the level of partnership, the public can negotiate and engage with the experts or decision makers, while at the levels of delegated power and citizen control the public has a majority vote or is in full control. With regard to the communication involved, the lower levels involve top-down communication and a one-way flow of information, while at the highest levels dialogue and two-way flow of information are involved (Rowe & Frewer, 2000).

**Table 2.3: The Ladder of Citizen Participation**[a]

| | |
|---|---|
| **8. Citizen control**<br>Participants have full decision making power and determine the agenda.<br>Participants are actively involved. Decision makers are facilitators. | } *Degrees of citizen power* |
| **7. Delegated power**<br>Decision makers share knowledge and expertise with participants to create new insights. Power and responsibility is for a large part in the hands of participants. Decision-makers have a facilitating and supportive role. | |
| **6. Partnership**<br>Participants cooperate with decision-makers to determine priorities and direction.<br>Decision makers take final responsibility for the process and end results of the issue. | |
| **5. Placation**<br>Key participants are involved, often in an advisory role.<br>Decision makers take control and in the end take the decisions. | } *Degrees of tokenism* |
| **4. Consultation**<br>Participants' are asked for input on their opinions and needs. Decision makers decide if and what happens with their opinions and needs. | |
| **3. Informing**<br>Participants are being informed about developments and plans. They do not have any influence on or say in the issue. It is a top-down, one-way communication process. | |
| **2. Therapy**<br>Participants can express their preferences. However, decision makers do not pay attention to their remarks. | } *Non-participation* |
| **1. Manipulation**<br>Participants get tasks assigned that have to be performed. Decision makers determine the agenda, manage the process and persuade the participants. | |

[a] Sources: Arnstein, 1969; Jacobs et al., 2005.

Thirdly, mechanisms of public participation have been evaluated by various authors (e.g. Chess & Purcell, 1999; Fiorino, 1990; Hanssen, Van Est & Enzing, 2002; Rowe & Frewer, 2000; 2004; 2005). Chess and Purcell (1999) stressed that a great variation in the criteria for success exists. Rowe and Frewer (2000) concluded that contextual and situational factors influence the effect that a certain mechanism of public participation can achieve (Rowe & Frewer, 2000). The authors distinguished criteria that should be used to select a participation mechanism. Process criteria are related to the construction and implementation of a procedure, and acceptance criteria indicate acceptance of the broader public (Rowe & Frewer, 2000). In later studies they evaluated effects of various public participation mechanisms (Rowe & Frewer, 2004; 2005), and described a typology of participation mechanisms. From the perspective of public understanding of science, not much research has been done yet to confirm the postulated effects of public participation. Hence, Rowe and Frewer (2004) pled for the establishment of a research agenda aimed at the evaluation of public participation mechanisms. Te Molder and Gutteling (2002) and Hanssen et al. (2002) argued as well that public participation efforts are dependent on the specific situation in which they are employed.

In short, public participation, and mechanisms that promote it, follow from a democratic rationale and are aimed at critical citizenship, empowerment of citizens, and above all, the gaining of trust by the public. The urge for public participation is underlined by many authors. The highest levels of participation are congruous with the objectives of empowerment, dialogue and two-way communication. But participation also depends on other criteria, such as power relationships (Arnstein, 1969), or, situational and other contextual factors (Einsiedel & Wambui, 2006; Rowe & Frewer, 2000; Te Molder & Gutteling, 2002).

### *2.2.4 Summary of the conceptual frameworks*

A comparison of the developments in the fields of risk communication, health communication, and public participation with those in the public understanding of science domain shows that, at a conceptual level, the same central ideas a role. Although the various models are known by different names (the deficit model, traditional model, traditional view or rational cognitive approach versus the interactive science model, democratic model, democratic view or new health promotion approach), in this thesis they will be referred to as the 'deficit model' and the 'interactive science model', respectively.

In all three research areas the role of the public differs, depending on the basic assumptions about the characteristics of the public. The public is either conceived of as a passive receiver, receiving information the same way that experts do (deficit model) or is an active participant and reacts in different ways that experts do (interactive science model). There is either a hierarchical relationship postulated between scientists and the public, with scientists playing the role of experts (deficit model), or the members of the public may be regarded as experts as well, with scientists fulfilling the role of coach or supporter (interactive science model). The communication process is either seen as a one-way, linear process aimed at persuasion (deficit model), or as an interactive, two-way or multi-way, process aimed at mutual understanding (interactive science model). Knowledge is either assumed to be fixed and certain, based on scientific expertise and thus referred to as 'sound science' (deficit model), or is surrounded by uncertainties, with different kinds of knowledge being present (interactive science model) (Kerr, Cunningham-Burley & Amos, 1998; Logan & Longo, 1999). Finally, trust is regarded either as a one-dimensional construct that does not receive much attention, and is not that important (deficit model), or it replaces knowledge as the main focus and is deemed to be crucial for building a long-term relationship (interactive science model) (Hansen, 2005; Hanssen et al., 2003; Te Molder & Gutteling, 2003).

In the previous pages, the general theoretical framework with regard to the public's relationship with science has been described. From the perspective of the public understanding of science, two models have been reviewed that articulate ideas about the public's relationship with science. The interactive science model is a response to conceptual and methodological problems within the deficit model, and both models are often presented as mutually exclusive alternatives. However, according to Hansen (2005) these two approaches often attribute different qualities to the same theoretical concepts.

In this thesis, in line with what other authors proposed (cf. Einsiedel & Thorne, 1999; Logan, 2001; Sturgis & Allum, 2004), the argument is made that both models are in fact not mutually exclusive. Einsiedel and Thorne (1999) regarded the two models as the polar endpoints of a continuum. In addition, Logan (2001) stated that:

> … the intent of the interactive science model is to underlie – rather than replace – the traditional view of the science communication process. The interactive science model does not quarrel with the idea that citizens should be better informed about science, nor does it overlook the important roles scientists […] and other professionals play in providing high-quality science information to the public (p. 157).

According to Logan (2001), the research field has been conceptually expanded by the existence of two models. And, as Sturgis and Allum (2004) argued, the two theoretical models might be integrated into a single, more complex and more complete account of the relationship between public and science (and, in their case, the knowledge-attitude dimension). Thus, following these authors, in this thesis the models are considered to be multidimensional theoretical models, within which concepts may take different positions depending on a range of influencing factors. In the next section, the different positions of some of these concepts will be examined in more detail.

## 2.3 Core concepts about the public and science

In this section, first, the concept of the public will be reviewed, and in particular the notion that it is not a single, homogeneous entity. Then, a closer look will be given at the concepts of scientific knowledge, and information and communication. The section will end with a discussion of some issues concerning the concept of trust.

### *2.3.1 Passive and active publics*

In line with what has been proposed by other authors, in this thesis the point of view is taken, that the public is not a single, homogeneous group of people, but rather a heterogeneous compilation of different publics (cf. Einsiedel, 2000; Millstone & Van Zwanenberg, 2000; Van Dijck, 2003; Willems & Regeer, 2007)[5]. Already in the 1950s, Dewey (1954, p. 33) emphasized that, "in no two ages or places are there the same publics". In Einsiedel's (2000, p. 207) words, "[p]ublics act in social contexts and shift their attention and knowledge with the rise and fall of a variety of issues". Van Dijck (2003, p. 185) has elaborated on this position and noted, "that the audience does not have just one identity, but that we inhabit overlapping identities – social, racial, sexual, religious, intellectual, and political – and no one of them alone consistently determines our responses or intentions".

According to Gottweis (2002) the varied and multi-faceted character of the heterogeneous public should be taken into account; it is "important to understand that 'the public' is a mythical construction which needs to be thoroughly reconsidered" (Gottweis, 2002, p. 668). He argued that publics are not something steady, but should be thought of as entities of a more fluid nature. Attitudes of publics change over time and are influenced by contextual circumstances and experiences. Hansen (2005, p. 106) expanded this notion by pointing out that, "'the public' is not a well-defined sociological entity, but a phenomenon that is actively constructed".

Neidhardt (1993, p. 348) pointed to the fact that, when considering the relationship between science and the public, science too, is a heterogeneous entity. The public

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[5] Due to the existence of countless connotations of the term 'the public' it is not within the scope of this thesis to give a comprehensive list of all possible meanings of the concept. Instead, it will suffice to provide a few examples to illustrate this complexity. Noelle-Neumann (1984) described three meanings of 'public': (1) Openness, universality, transparency, an open place, a public path; (2) In the context of public rights and public power, public is related to state involvement, public interests, i.e., issues that concern us all; (3) In the context of public opinion, the prevalent notion.

Hansen (2005, p. 106) also reviews the meanings of the word 'public'. He briefly described three of them by contrasting the term to several opposites of the word. First, public as opposed to secretive, which means that something is transparent and open to scrutiny by all. Second, public as opposed to private, and thus pointing to something that is of collective concern. Third, public can be considered as 'Publikum', as the object of the decrees of authorities or the audience of mass-mediated messages.

exercises a different mode of communication with their public discourse than scientists do with their scientific discourse. This may lead to problems, especially in cases where science participates in public controversies or those which are dealing with fundamental questions in life. The communication problem between the general public and science is obvious and fundamental (Neidhardt, 1993, p. 348).

Both models in public understanding of science took into account that the public is not a single, homogeneous entity, but rather is a heterogeneous in nature and consists of various publics in various roles. Both classified different groups, or publics, within the general public (J.D. Miller, 1993; Wynne, 1995, p. 364). In the deficit model, J.D. Miller distinguished three types of general public, namely an attentive public, an interested public, and an inattentive public, since a public can never specialize in more than a few issues (J.D. Miller, 1993). In the interactive science model the public is regarded as an active public with its own expert knowledge, as Wynne argued in his influential article on Cumbrian sheep farmers (Wynne, 1989). His ideas about the contextualization of knowledge implied that not only the concept of 'science' has to be investigated, but also that of 'understanding', and thus, the concept of 'the public', since it made clear that "there are countless 'publics' of science" (Wynne, 1995, p. 364). Einsiedel (2000) agreed that, in many circumstances, publics are diverse, have expertise, and are attentive and motivated, but she stressed that, in other situations, they may be inattentive, unmotivated and ignorant. Hence, the relationship between the public and science is far more complex than was previously believed.

### *Ways to classify publics*

J.D. Miller's division of the general public into three types (J.D. Miller, 1993) was based on the model of George Almond (In De Loor, Midden & Hisschemöller, 1992). Almond described public participation in the decision-making process. His model is shaped as a pyramidal construction with decision makers on top, followed by a somewhat larger group of policy leaders. The top group of decision makers in charge of making decisions is often comprised of governmental parties or industrial actors. The policy leaders consist of prominent persons, i.e., experts, in science and technology and societal organizations. Both groups hold expert knowledge and are often in contact with each other. Below these two top layers, the three layers of the general public can be found. The *attentive public* is composed of individuals interested in a particular issue and willing to become and remain knowledgeable about it. J.D. Miller (1983) argued that this public has reached the desired level of scientific literacy.

Next, there exists an *interested public*. This public is not well informed, but shows interest in scientific issues. Lowest in the pyramid, is the largest group, the *inattentive* *public*. This is the passive public that has no interest in scientific and technological issues and has not reached the level of scientific literacy desired by the researchers (J.D. Miller, 1983, Prewitt, 1982). However, this public needs to be taken into account for the reason, as it may exercise a political veto, and – as the case of biotechnology has shown – this public may be so influential that politicians are forced to make decisions that are in agreement with these publics' wishes. For authors like J.D. Miller (1983) these were reasons why it was important to expand scientific literacy for the inattentive public, for the interested public, as well as for the attentive public (cf. De Loor et al., 1992). Prewitt (1982, p. 13) added to these reasons the fact that science is a case of public consequence.

While J.D. Miller (1983) assumed that knowledge is the main factor that affects the public's attentiveness, there are other conditions that may influence public's attention for science and technology issues (Hornig Priest, 2006). In their 'knowledge gap theory', Tichenor, Donohue and Olien (1970) proposed that people process information in different ways, thus creating a knowledge gap. However, when people become interested in an issue, this gap can be closed since people are able to process the required information (Hornig Priest, 2006; Tichenor et al., 1970). Gaskell and Bauer (2001, p. 63) explained this varying interest in an issue among different segments of the public as the result of 'issue specialization' (cf. Converse, 1964). They called an 'engaged public in biotechnology', a public that is more likely to be better informed, to seek new information, and to have more resistant attitudes, i.e., a public that is more strongly opposed to the issue at hand, and is thus more likely to participate in political processes than the general public (Gaskell & Bauer, 2001).

Instead of classifying different kinds of publics based on people's attentiveness to a scientific issue, alternatively, it may be subdivided by means of their *involvement* in an issue (De Loor et al., 1992). De Loor et al (1992, p.33) defined involvement as the interest an individual has in a subject. The authors distinguished between two types of involvement: personal involvement and issue involvement. According to De Loor et al. (1992, p. 33-34), personal involvement is stronger than issue involvement, which means that the issue has personal (and important) consequences for an individual. For example, people will feel more involved in a decision that affects their own neighbourhood than something that only affects another part of the world.

With regard to issue-involvement, when the issue has no direct and personal consequences or when these are not immediately clear, but the issue is regarded as being of social concern, people feel involved. Biotechnology is a typical example of an issue that attracts issue-involvement. Many people feel involved in biotechnology, not because it affects them personally but because it is a theme of general importance that influences society as a whole (De Loor et al., 1992). The concepts of attentiveness and involvement appear to be closely related.

Additionally, in the Elaboration Likelyhood Model (ELM model) developed by Petty and Cacioppo in 1986 (e.g. Cacioppo, Petty, Kao, & Roderiguez, 1986; Littlejohn & Foss, 2005), understanding the involvement of people in an issue is important for finding out if people evaluate information in an elaborate and critical way when involved in an issue (central route) or in a less critical manner, in cases where there is less involvement (peripheral route).

A third way to classify publics has been by means of people's roles with regard to science issues. Depending on the circumstances under which people are confronted with a new technology, such as biotechnology or genomics, people can be attributed to various roles, for example, that of a citizen influencing decision making, that of a consumer buying products, that of a patient being ill (De Loor et al., 1992). Felt (2000) stated that the public may adopt different roles depending on the particular functions it has to fulfil in relation to the way science is seen. She indicated that publics easily shift roles, and, consequently, that a mixture of roles is the rule. One moment people are consumers, the other moment they are citizens, and yet another moment they act as spectators, witnesses, or participants.

This mixture of roles has also been emphasized by Hill and Michael (1998). In the context of biotechnology and genetic engineering, they saw the public as "… the figure of the 'layperson' that is an admixture of (at least) an autonomous, thoughtful citizen and a concerned, rational decision-making consumer" (Hill & Michael, 1998, p. 213). The level of involvement tends to be related to the roles people accept or embrace.

### *2.3.2 Scientific knowledge*

The two models conceptualized scientific knowledge in different ways. As it was shown, followers of the deficit model argued that more scientific knowledge leads to a more positive perception of this science (Hamstra, 1995). Followers of the interactive science model did not see this direct relationship between knowledge and perception. None of the authors, from neither model, denied the importance of knowledge in itself. According to Felt (2000, p. 13), both models have had two basic assumptions of 'the public' in common. Both agreed that the public is ignorant of scientific knowledge to a certain degree and that, at the same time, the public has the desire to know.

As has been discussed above, the earliest critics of the deficit model pointed either to the fact that science is not sharply defined (e.g. Silverstone, 1991; Wynne, 1991; Ziman, 1991), or to the fact that science is a special kind of knowledge, as argued by J.D. Miller (1983) and others. The deficit model takes into account the formal contents of scientific knowledge, but not the forms of institutional embedding, patronage, organization, and control (Wynne, 1992).

The interactive science model also considers the contextualization of scientific knowledge. Knowledge is part of a complex and varied response (Ziman, 1991). Different knowledges exist (Hansen, 2005) or, as Sturgis and Allum (2004) have put it, "[k]nowledge of science is not seen as an abstract canon of 'facts', but as sets of understanding within varying practical and social contexts. […] That means that other knowledges are always moderating factors" (p. 69).

Nowotny, Scott and Gibbons (2001) have further elaborated the concept of knowledge. These authors agreed that, in contemporary society, a fundamental change occurred in the production of (scientific) knowledge (e.g. Gibbons, 1999; Nowotny et al., 2001). Based on the increasing contextualization of knowledge production, they labelled this change *Mode 2 knowledge production* or *Mode 2 science* as opposed to *Mode 1* (Nowotny et al., 2001). Instead of 'objective' knowledge as it used to be in Mode 1, they claim knowledge to be *socially robust knowledge,* meeting other socially embedded standards in Mode 2. Thus, in the opposing ideas of fixed knowledge versus embedded knowledge constructed from various sources the diverging ideas about knowledge in the deficit model and the interactive science model are shown.

What are the implications of these ideas about science and knowledge for the relationship between the public and science? According to Gaskell and Bauer (2006), the separation between lay and expert knowledge in the deficit model of public understanding of science is not a simple one, and "it should be recognized that lay-expert hierarchies are not simple power relations defined over who does know (experts) and who does not know (lay) …" (p. 23). Due to the complexity of the issue and to the fact that there is too much too know, it is quite conceivable that experts in one particular field are at the same time lay people in another field. Gaskell and Bauer (2006) acknowledged that several types of expert and lay knowledge must be recognized, as Wynne and others have argued (Wynne, 1995, 1996; Irwin & Wynne, 1996).

Public (risk) perceptions and attitudes toward new technologies such as biotechnology have become increasingly important for a range of different actors (e.g., governments, industry, NGOs). For example, governments are becoming more and more dependent on public support for policies, while public perceptions are critical, and industry depends on marketing successes, since perceptions and attitudes affect consumer behaviour as well. Due to the different interests of various actors involved, there are many ways to study public perceptions and attitudes (Hamstra, 2000; De Loor et al., 1992).

In much of the research, especially in quantitative survey studies, the controversy between lay people and experts features prominently, with lay people showing sceptical attitudes towards experts, who operate strictly based on scientific knowledge (Hansen, 2005). Based on the deficit model, premises in this kind of public perception and attitudes research were that a more educated and informed public will be more positive about the new technology (Hamstra, 1995). Consequently, this public perception research had a strong cognitive basis. According to Hansen (2005), in the deficit model, assumptions in the initial cognitive oriented research have been modified. It was recognized that experts themselves do not work according to scientific standards, but in their research they build in normative assumptions about the public. In addition, the multidimensionality of a related area such as risk perception has been increasingly acknowledged and implemented (Slovic, 2000). As Slovic (2000) argued:

> The public is not irrational. The public is influenced by emotion and affect in a way that is both simple and sophisticated. So are scientists. The public is influenced by worldviews, ideologies and values. So are scientists, particularly when they are working at the limits of their expertise (p. xxxvi).

Conceptually, public (risk) perceptions and attitudes are not one-dimensional phenomena, but, instead, are often thought to overlap and influence each other. De Loor et al. (1992) argued that asking people about their attitudes corresponds not only to asking for perceptions, but perceptions and attitudes can provide insight in people's behavioural intentions, while interest and knowledge of scientific developments are important conditions for both the development and the quality of perceptions and attitudes. Knowledge and interest are also important in defining behavioural intentions. Involvement with an issue, amongst others reflected in knowledge and interest, will increase the chance that people turn perceptions and attitudes into behaviour, for example talk to other people about the issue, buy a product, or show their behaviour in other ways.

### *2.3.3 Information and communication*

According to Logan (1999) and Einsiedel and Thorne (1999), in the deficit model communication is considered a linear, top-down, one-way transmission of information with the goal to persuade the receivers. Proponents of the interactive science model, on the other hand, argued that communication is instead a two-way or multi-way flow of information aimed at dialogue and mutual understanding. Their emphasis has been less on informing people, but instead aimed at improving communication among citizens, scientists, politicians, government and corporate officials, and journalists.

This way of thinking about communication is influenced by Carey (1989, cf. Logan, 1999), who was one of the first to emphasize that, apart from a process of sending information, there is also a ritual role of communication. Carey (1989) labelled the process of sending information the 'transmission view of communication'. The medium is an instrument for disseminating news and knowledge. The 'ritual view of communication' focuses on different issues: communication is linked to terms like 'participation' and directed toward the maintenance of society over time, the representation of shared beliefs, where reality is produced, maintained and transformed. Communication is not a reflection of reality, but the very means by which reality is created (In Hanssen et al., 2003). However, the ritual view did not exclude the process of information transmission; rather it contended that one cannot understand the process of information transmission if one does not include the larger context of at least some notion of the place of ritual action in social life (Carey, 1989, p. 21, 22).

Rowan (1994) discussed the communication models in use in technocratic and democratic risk communication. Technocratic risk communication emphasizes accurate information: therefore, their communication goals are informing and persuading. According to Rowan, the strength of this model has been its respect for information gathering and the scientific way of thinking. However, in her eyes, the overemphasis on the importance of accurate information is a problem. This is too narrow a way of seeing risk communication.

In contrast, democratic risk communication sees communication as a process of maximum participation and power in decision making by means of sincere dialogue. It assumes that a fair process equals a fair product. Therefore, communication goals are listening and mutual understanding by means of dialogue, while persuading is ruled out. According to Rowan (1994), the democratic model fails to recognize the importance of knowledge (which is a minimal level of understanding of the problem), communication and negotiation skills. At the same time, it underemphasizes the use of persuading. In some cases, a communication goal such as persuasion may be useful. It would be better for participants to pursue all communication goals, such as self-expression, listening, informing, entertaining, negotiating and persuading.

In Rowan's (1994) opinion, in the technical view, communication has been reduced to information transmission, but in the democratic view, the strong emphasis on participation according to rules for fair procedures and the ruling out of persuasion is too rigid as well. It is important to establish credibility (i.e., to develop trust), to inform (i.e., to enhance awareness and understanding) and to persuade (i.e., to motivate agreement and action) when necessary.

### *2.3.4 Trust in science*

Finally, trust is not an issue that attracted much attention in the deficit approach. Science was seen as infallible and trust was taken for granted. However, with the rising prominence of the interactive approach, the concept of trust has gradually been starting to replace the idea of a knowledge deficit as one of the explanations for the controversy regarding biotechnology and genomics (Hansen, 2005). As Neidhardt (1993) argued about the differences between the public and science:

> When science meets the public, the public cannot really understand what science says. On the other hand, the public has to discuss and to judge scientific information when it deals with matters of general interest. In these situations, the public is expected to accept what it cannot comprehend (p.348).

He offered a suggestion for a solution: “When people cannot understand, they have to believe. And whether they believe or not is a matter of trust” (Neidhardt, 1993, p. 348). Trust is compensation for communication deficiencies on a cognitive level. Science has to work based on trust (which is a complex and difficult process).

An apparent paradox presents itself. On the one hand, societies increasingly depend on science-based knowledge; on the other hand, confidence of societies that scientists can deliver that knowledge is in decline (Hansen, 2005, p. 54). In both the literature based on the interactive science model, and that on risk communication, health communication, and public participation, trust became a key issue (e.g., Rowan, 1994). For example, Slovic (1993, p. 677, 680) argued that trust is more fundamental to conflict resolution than is risk communication. And once trust is lost, it may take a long time to rebuild it to its former state. This rebuilding should be based on openness and involvement with the public, going beyond public relations and two-way communication, directed at levels of power sharing and public participation in decision making. According to Te Molder and Gutteling (2003, p. 123) public trust is, “the final referee that decides whether and how a technology develops in the community”.

Trust is a complex concept and several aspects can be distinguished. Luhmann (1979) saw trust as a mechanism that reduces social complexity. According to Luhmann (2000, p. 95), trust is a solution for specific problems of risk, thus trust presupposes a situation of risk and is based on a circular reaction of trust and action, both being complementary requirements (Luhmann, 2000, p. 100). If trust is lacking, it changes the way people make decisions about important issues, it influences actions, and thus, it influences society, the system (Hansen, 2005, p. 100; Luhmann, 2000, p. 103).

Whereas Luhmann (1979, 2000) considered trust as a mechanism and elaborated on aspects of trust at a rather abstract level, Earle and Cvetkovich (1995) and Sztompka (1999) discussed (aspects of) trust at a more practical and individual level. Earle and Cvetkovich (1995) distinguished interpersonal trust, as based on interaction between individuals, and social trust as all other trust, increasingly needed in more complex societies. Both types of trust often operate hand-in-hand. Sztompka (1999) defined trust as, “a bet about the future contingent actions of others” (p. 25), and described various types of trust. Apart from personal trust, as a first group of trust types, he distinguished among categorical, positional, group, commercial and systemic trust. These types of trust function according to the same logic, and in the end, all types rely on people and their actions (Sztompka, 1999, p. 46).

Next to trust based on direct human actions, which Sztompka (1999) called primary targets, he described secondary targets of trust, which are objects that people put their trust in by means of trusting primary targets of trust (for example, reviewers in a scientific peer review system are trusted to be reliable, which causes the peer review system to be trusted). These indirect references to trust are possible by means of what he called 'pyramids of trust' (e.g., the expert is trusted because he works at a respectful university) or 'agencies of accountability' (e.g., agencies such as courts, police, consumer organizations provide trustworthiness of governments and so forth, but need to be trusted first) (Sztompka, 1999, p. 46-48). Just like Earle and Cvetkovich (1995), Sztompka (1999, p. 51) observed that "the balance of trust and distrust for a given agent is always very complex and sometimes ambivalent".

With regard to the relationship between the public and science, one element of trust will be discussed in more detail: trust in the scientific system. According to Yearley (2000), the scientific community depends on trust. The whole system of scientific research, with peer review, and so on, is based on trust in people, in machines, and in assumptions. When creating new knowledge, no one may fully know which factors are going to be influential. Yearley (2000) gave two reasons why trust is important. First, the importance of trust can be seen from looking at abnormal conditions where all assumptions are doubted. Second, as Shapin (1994) has argued, the founding of institutions of science in the 17th and 18th century depended on new conventions of trust and civility. Consequently, the building of scientific knowledge depends on trust (Yearley, 2000). Yearley argued that trust is central to the business of science itself. Trust is not restricted to the lay audiences, but it is an essential element of scientific knowledge. Neither is trust a fixed disposition, but instead, trust and credibility are the outcome of interactions and negotiations (Yearley, 2000, p. 227).

## 2.4 Provisional analysis of the core concepts

A provisional analysis of the core concepts in public understanding of science has shown that, at the conceptual level, between the deficit model and the interactive science model, several differences exist. Indeed, in both models different qualities are attached to the same concepts. In this research project the focus will be on the concepts that are summarized in this section.

*Passive and active publics*

Both models acknowledged that the public is not a homogeneous entity, and ascribed different roles to the public. In the deficit model, the public was divided into different categories: attentive, interested and inattentive (J.D. Miller, 1983). The inattentive public, and less so the interested public, are both categories with a knowledge deficit that need to be resolved. In the interactive science model, the role of the public varied according to time, place and circumstance and has been considered an active public (Wynne, 1989). However, Yankelovich (1982) and Einsiedel (2000) have argued that publics may be inattentive, unmotivated and ignorant, which makes the relationship between public and science more complex.

*Scientific knowledge*

Scientific knowledge is considered important in both models. But, whereas, in the deficit model scientific knowledge is based on facts, certain, and sound science, in the interactive science model this knowledge is regarded as one of more types of knowledge, and not sharply defined. These other knowledges are always moderating factors, functioning as sets of understanding within varying practical and social contexts (Sturgis & Allum, 2004). Therefore, scientific knowledge holds a less exclusive, less expert position in the interactive science model, than is the case in the deficit model.

*Information and communication*

Information and communication hold different positions in the two models. In the deficit model, communication is a one-way flow of information, aimed at persuading the public. Scientists know which information is best for this public. The interactive science model, like in democratic risk communication, believes that persuasion is not permissable; instead, information should be a shared experience of dialogue and mutual understanding. Communication (two-way) and information (one-way) are found on both extremes of the continuum, but according to Rowan (1994) it would be better to consider on a case-by-case basis which communication strategies to use.

*Trust*

Finally the conception of trust has changed, from a one-dimensional and not so important factor in the deficit model, to a complex and critical factor in the interactive science model, due to the public's lack of trust in science and other actors. Some authors even referred to this development as a shift from a 'knowledge deficit' to a 'trust deficit' (Hansen, 2005, p. 100).

Before turning to the empirical studies, in the next chapter (Chapter 3), methodological issues will be discussed. As has been mentioned before, each model takes the position that the methodology used by the other model is inadequate for doing research. Therefore, several authors (e.g., Einsiedel, 2000; Logan, 2001; Von Grote & Dierkes, 2000) pleaded for a multi-method approach as they believed that methodological pluralism is key for future research in the field. Qualitative and quantitative studies should be integrated more closely than they have been so far, and the entire spectrum of methods available for the social sciences should be used (Von Grote & Dierkes, 2000).

# Chapter 3

# A mixed-method approach

*In this chapter the methodological approach used in this thesis will be discussed. After key developments in mixed methodology are described, it will be expounded how a mixed-method approach can contribute to a multifaceted picture of the public and its relationship with science. Following this, the advantages and disadvantages and the aims of the methods in this thesis are briefly described. The methodological approaches are discussed in more detail in the empirical chapters.*

## 3.1 Introduction

Several authors in the public understanding of science domain have advocated a mixed-method approach when doing research (e.g., Einsiedel, 2000; Logan, 2001; Sturgis & Allum, 2004; Von Grote & Dierkes, 2000). They considered methodological pluralism – which combines qualitative and quantitative methods – as promising and viable, since it can contribute to the theoretical expansion of existing conceptions, and deepen the understanding of the public's relationship to science. In this chapter, the rationale for mixed methodology is discussed (3.2), as is the added value of using mixed methodology for the main topic of research that is examined in this thesis (3.3).

## 3.2 Mixed methodology

In the social and behavioural sciences, the past few decades have seen changes with regard to the procedure involved in the choice of research methods. According to Tashakkori and Teddlie (2003), for a long time, the dominance of the positivist- empiricist paradigm resulted in the almost exclusive use of quantitative research methods, known as the hypothetico-deductive approach (Patton, 2002). Since the 1980s, or, according to others earlier, already from the 1950s onwards (cf. Erzberger & Prein, 1997; Greene, Benjamin & Goodyear, 2001), a paradigm of constructivism and phenomenology emphasized qualitative methods of research, also known as the holistic-inductive approach (Patton, 2002; Tashakkori & Teddlie, 1998, 2003). The rise of qualitative research methodologies led to debates between proponents of the quantitative and those favouring an alternative, qualitative one. Issues of contention concerned the methods of study, rigor of the procedures involved and the validity of the outcomes (Patton, 2002; Tashakkori & Teddlie, 1998, 2003). Tashakkori and Teddlie (2003) have argued that, as a result of these debates, the field of mixed methodology evolved out of a worldview of pragmatism. Mixed methodology is now considered a valid and valuable research strategy and it has been used extensively in the areas of education and health (Moran-Ellis et al., 2006; Tashakkori & Teddlie, 2003).

According to Greene et al. (2001), not only pragmatic reflections, but also other paradigms motivated the choice for mixed methodology. For example, in the dialectic view, the value of both paradigms is appreciated, and, in order to contribute to a better understanding, their methods are integrated. Advocates of the substantive view argued that methods should be chosen that best address the problems under investigation. Subsequently, in the view of the alternative paradigm, mixing methods amounted to 'good practice' and 'better understanding' (Greene et al., 2001, p. 28). Yet, referring to the level of paradigm Greene et al. (2001, p. 28) argued that although in theory a method does not have to be associated with a particular worldview, in practice it often is.[1] The implications of this for the choice for methods in the present research project will be discussed at the end of this chapter. First, the reasons for choosing mixed methods will be explained.

According to Greene et al. (2001, p. 30), when choosing methods for a particular study the consideration of reasons for using mixed methodology is another step in this process. They distinguished an overall reason, i.e., a better understanding of the phenomena under study, and a greater reduction of uncertainty. They specified what better understanding may entail, namely:

- *Enhanced validity and credibility of inferences.* Different methods are used to measure the same phenomenon to create a convergence of results and increased validity (the classical idea of triangulation,[2] i.e., the multiple measurement of the phenomenon under study (Brewer & Hunter, 2006)).
- *Greater comprehensiveness of findings.* Different methods offer different lenses for illuminating more dimensions or facets of the same phenomenon.

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[1] Although their claims have not been investigated, the opposing camp have criticized the use of methods in the field of public understanding of science by pointing to this mixing up of worldview (and thus theoretical preferences) and methodology (Sturgis & Allum, 2004; see Chapter 2).

[2] Triangulation, first used in geodesy, originally stands for the procedure that three measurements can determine the exact position of a point in the landscape and was invented by Gemma Frisius from Dokkum in 1533 (Haasbroek, 1968; Patton, 2002). In the social sciences, the meaning of triangulation has been broadened from an idea of enhanced validity to the idea that different results reflect different *aspects* of a phenomenon. However, the term triangulation is sometimes used without referring to an underlying idea about the use of mixed methods (Moran-Ellis et al., 2006).

- *More insightful understandings.* In stead of convergence, different methods show differences or conflicting factors (divergence) and draw attention to new analytic questions (Patton, 2002).
- *Increased value consciousness and diversity.* Different methods lead to pluralism and to critical commentary and public debate about the phenomenon under study.

Other authors, such as Erzberger and Prein (1997) and Moran-Ellis et al. (2006) identified similar reasons, such as increasing validity, creating or integrating new knowledge by means of synthesis of the findings, bringing to light multiple facets and reflecting the complexity of the phenomenon, establishing a more complete picture of the phenomenon, or implementing a more robust theoretical framework.

A next step in the process of choosing research methods that Greene et al. (2001), mentioned is the choice of the specific type of mixed-method design. In a *coordinated design*, the mixing of the methods happens, in essence, at the end, i.e., in the analysis stage. And, one set of findings mainly serves to explain or refine other sets of findings. In an *integrated design*, interaction between methods is planned and occurs throughout the study. Analysis may take place in parallel tracks, by analyzing data sets separately and making comparisons and connections in the conclusion stage, or in crossover tracks, when results are used in further analysis. It leads to a greater synthesis rather than reporting of findings from each method separately (Greene et al., 2001).

Moran-Ellis et al. (2001) defined this latter design somewhat differently. They argued that integration requires two conditions; one is that the different methods are given equal weight and the other that operationalizations within these methods are oriented towards a common goal or research question and thus influence each other. In addition, the methods may be conducted simultaneously or sequentially, but this does not affect the integration of methods. Therefore, Moran-Ellis et al. (2001) reserved the term *integrated methods* for those methods where integration occurs from the point of conceptualization onwards and across all phases of research, and used the term *analytical* or *interpretive integration* for the mixing of methods at the level of analysis or theory.

Green et al. (2001) acknowledged that, in the practice of choosing methods, these paradigms, reasons and designs cannot be sharply distinguished. Often the final design and analysis depend on a combination of factors, including restrictions of time and money. In practice, mixed methodology therefore is much more complex and dynamic than the theoretical conceptions about mixed methods would suggest. In the following section, first a short reflection on the choice of method in this research project will be presented, before the actual choice of methods is discussed.

### 3.3 Reflection on the choice of methodology

From the perspective of public understanding of science, two models have been available for the analysis of the relationship between the public and science. In practice, most studies based on these models restricted their methods of research to either quantitative methods (deficit model), or qualitative methods (interactive science model). Proponents of the interactive science model did not only criticize the advocates of the deficit model at the conceptual level, but also its methods were questioned (cf. Sturgis & Allum, 2004). The strongest opponent of the use of quantitative methods has been Wynne (1995, p. 370), who stated that large-scale surveys of public attitudes towards science – and understanding of science – inevitably build in certain normative assumptions about the public, science, scientific knowledge, and understanding. Wynne (1995) argued that, by nature, surveys take the respondent out of the social context and, hence, are unable to examine which meanings concepts have for respondents. According to him, the survey method incorrectly assumes that meanings exist independent of respondents' social interaction.

However, it can be argued that it is not only surveys that isolate respondents from their social contexts; this is unavoidable as it is inherent in *all* methods of (social) scientific research that the limitless complexities of the social context cannot adequately be done justice (cf. Erzberger & Prein, 1997). Furthermore, according to Brewer and Hunter (2006) each research method is able to address questions of measurement and theoretical adequacy but "none of the methods can provide the data required to measure all the variables and test all the hypotheses that might possibly be pertinent to determining a theory's validity (p. 30)". They argued that each method gives access to some variables and hypothesis, failing to give access to others. No method is without bias, but each method has its own weaknesses and strengths (Brewer & Hunter, 2006; Erzerger & Prein, 1997).

In addition, other authors in the public understanding of science research (cf. Peters, 2000; Sturgis & Allum, 2004) critically assessed the use of surveys, but they argued that both types of methods – qualitative and quantitative – should be used in conjunction with each other in order to broaden the research on the public understanding of science. They pointed out that confusion of theory and method is unnecessary, unhelpful and avoidable (Sturgis and Allum, 2004). Von Grote and Dierkes (2000) argued that conceptual questions such as formulated in the current studies on the public understanding of science and technology, require qualitative research methods as well as quantitative research methods. Therefore, they considered methodological pluralism crucial for future research efforts aimed at acquiring better theoretical understanding of concepts (Von Grote and Dierkes, 2000, p. 357).

The choice of the empirical studies in this research project was informed by the criticisms raised against the single-method approaches and the pleas for alternative, multi-method designs (cf. Einsiedel, 2000; Logan, 2001; Von Grote & Dierkes, 2000). The overall goal of the research discussed in this thesis was to make a contribution to the theoretical understanding of the relationship between the public and science. With this goal in mind, three specific research questions were formulated. Each specific research question provided a different perspective, or offered a different lens, for analyzing the same general question. Thus, taken together, the use of these three different perspectives made it possible to create a greater comprehensiveness of findings and more sophisticated insights in the scientific understanding of the relationship between the public and science.

### *Publics' role in Dutch biotechnology debates*

The first question, about the role of publics in Dutch biotechnology debates, aimed at providing the overall context for the further studies – the state of the art – and an initial exploration of the theoretical concepts. The debates have been organized in the recent past. Therefore, collection of data by means of direct observation was not possible anymore. Instead, a document analysis was carried out that could provide an answer to the research question for two reasons. First, documents have proven to be valuable sources of data in their own right, because of what can be learned directly from them. And, second, they "provide the evaluator with information that cannot be observed anymore" (Patton, 2002, p. 294).

### *Publics' considerations about gene research*

The second question, addressing publics' considerations about (communication aspects of) gene research, aimed at gathering a palette of opinions. Exploratory methods were appropriate for such a purpose. Focus group discussions could fulfil this goal since this is an exploratory method, capable of showing a broad range of views, useful for understanding the different perspectives held by the participants (Downs & Adrian, 2004; Kerr et al., 1998). Focus group discussions enable discussion, debate, and interaction among participants, encouraging them to talk about something they might not have previously considered in depth, such as gene research, for instance. Focus group data are suitable for uncovering differences in perspectives as well as the factors that influence these perspectives. Other methods, such as interviews – which are more useful when it concerns well-known issues –, or the Delphi technique – aimed at at reaching consensus –, are less appropriate to the objectives of this study. Focus group discussions were the method of choice for addressing the research questions at hand, since they are able to explore subtle differences in people's conceptions (Bloor, Frankland, Thomas, & Robson, 2001).

*Publics' participation in gene research*

Finally, the third question about the way in which publics differ in their relationship with gene research when actively or passively participating in this research, is aimed at a more precise description of the differences between various publics and science, based on the former studies. Survey methodology should be able to provide an overview of a population by means of systematic observation and description of a (part of) that population, and, therefore, is perfectly suitable for the purpose of this study (Hüttner, Renckstorf, & Wester, 1995).

Thus, by incorporating both pragmatic and substantive arguments, the design of the present studies in this research project is derived from the same general research objective of achieving greater comprehensiveness of findings and more insightful understandings. Data were collected sequentially, and each study addressed the same general research question, but focused on a particular aspect within this question. The analyses were first carried out separately, in order to benefit the design of subsequent studies by previous ones. In the end, the different analyses were integrated when they were related to the theoretical concepts and when the discussion of the main conclusions took place. The three methods have thus been given equal weight in their contribution to the theorizing of the relationship between publics and science. This design represented a type of integrated design, although not in pure form.

In the next three chapters (Chapter 4, 5 and 6), the empirical studies will be described. The conclusions of the separate studies will be presented at the end of the respective chapters, in order to build on these in the following studies. General conclusions will be drawn in the final chapter (Chapter 7). Where, amongst other things, a comparison between methods is made and connections are exemplified.

## *Chapter 4*

# The publics' role in Dutch biotechnology debates

## A document analysis

*In this chapter, as a first step in investigating the publics' relationship with science, a document analysis of the Dutch public debates on biotechnology was conducted. Between 1993 and 2001, five debates took place. The roles the general public and scientists played in these debates were analyzed. The public's influence in the decision-making process was investigated. Furthermore, the communication process and the notions of trust and knowledge during these debates were considered. Results showed that there was only a small active and participating public. This active public hardly had any influence on decision-making processes. Scientists mostly fulfilled an expertise role. The communication consisted both of one-way and two-way communication processes. Knowledge – as in the deficit model aimed at informing and persuading the public – still played an important role. Trust was considered complex and important.*

### 4.1 Introduction and research questions

In the introduction it has been shown that the publics' relationship with science, and especially with biotechnology and genomics, is complex due to their changing relationship. Science's credibility and the public's trust are no longer self-evident (Beck, 1992; Giddens, 1990). In order to gain more insight in the public's relationship with science – and thus to better understand the underlying concepts in the two models from public understanding of science – the first specific research question was formulated:

*RQ1: Which roles did publics play in Dutch biotechnology debates?*

With regard to these roles, a document analysis of Dutch public debates on biotechnology could provide an answer to the question. As has been pointed out in Chapter 2, the roles vary within publics, but the emphasis is placed on the public in its passive versus its active role. Participation from the active public is, amongst other things, related to the influence this public has on the decision-making process and the trust the public puts in science. Therefore, based on the specific research question and the theoretical framework presented in Chapter 2, the following empirical research questions were formulated:

*RQ1a:* *Which roles did the general public and scientists play in Dutch biotechnology debates?*

*RQ1b:* *Which influence did the general public have on the decision-making process that resulted from the public debates?*

*RQ1c:* *How were communication processes designed in these public debates?*

*RQ1d:* *Which roles did knowledge and trust play in these communication processes?*

In the following sections the methodology used in the document analysis is described (4.2), the results of this analysis are presented (4.3), and conclusions are drawn (4.4).

## 4.2 Design of the document analysis

The literature on the biotechnology debates in the Netherlands was reviewed. Firstly, materials bearing on the Dutch debates on biotechnology that have been published in academic journals, from the start of the debates in the 1980s until 2005, were systematically selected. To gather academic references to the public debates on biotechnology, the electronic reference databases Web of Science (which contains the ISI Social Sciences Citation Index, ISI Science Citation Index and the Art and Humanities Citation Index) and Scopus (a reference database that contains articles from both the social sciences and the sciences) were used. Since these two databases cover a broad range of journals from many disciplines, it was expected to find as much as possible of the peer-reviewed literature published on the Dutch public debates on biotechnology. All databases were searched using the main search terms *biotechnology* and *public debate* in combination with terms that related to these two main search terms. Related terms of biotechnology, and public debate were found via a thesaurus of index terms. The search was restricted to articles that were in some way related to the organized debates held in the Netherlands.

Secondly, as academic sources alone would not provide all the information required, in addition to the peer-reviewed literature, (unpublished) reports and similar materials on the debates were searched for. References found in the articles and reports were then checked for further relevant articles or reports. All results, together with several descriptive characteristics were put into an Endnote database. At this stage, articles and reports were removed that were double or triple references, book reviews or editorials, or not related to the biotechnology debate in the Netherlands. Altogether, 54 documents were acquired in this way which, which formed the basis for the analysis (see Appendix 1).

### *Frame of analysis*

The document analysis focused on the main concepts used in the two models in the research area of public understanding of science. Based on the theoretical framework (see also Chapter 2) these main concepts concerned the relationship between the general public (lay public) and scientists (experts), their respective roles and their influence on the decision-making process. It also concerned the communication process by means of looking at information and communication. Scientific knowledge and trust were concepts attention was paid to. Some contextual information was included well. All material was analyzed according to the scheme described in Table 4.1.

**Table 4.1: Scheme of the document analysis**

| *Themes and issues* | *Questions* |
|---|---|
| **Organization of the debate** | What is the theme of the debate?<br>What is the goal of the debate<br>How is the debate organized?<br>Who has organized the debate?<br>Which communication and public participation mechanisms are used? |
| **Attitudes and perceptions** | Which attitudes and perceptions does the general public have towards the theme of the debate? |
| **Actors and roles** | How is the 'general public' described?<br>Which roles does the public fulfil?<br>How are scientists described?<br>Which role do these scientists play?<br>How is the relationship between scientists (expert) and the general public (passive or active public) considered in terms of hierarchy?<br>Which other actors are involved? What are their roles? |
| **Level of participation (influence/ power)** | How is the public involved in the decision-making process?<br>How much influence does the general public have on the final policy?<br>Which arguments are given for providing (or denying) the general public opportunities to influence policy? |
| **Level of institutionalization (influence/ power)** | Who organizes the debate?<br>Which organizations or groups stimulate the debate?<br>How is the debate funded?<br>What is the resource base?<br>Do public funds contribute?<br>Is the possibility for public participation enacted in laws or policy statements?<br>Is the possibility for public participation structurally supported? |
| **Communication process** | Which type of communication process is dominant in each debate?<br>Which role does the communication content play in each debate? |
| **Knowledge** | Which type of knowledge is seen as important in the debates?<br>How important is the role of (which kind of) knowledge? |
| **Trust** | How is trust perceived, as a one-dimensional construct or as a multi-dimensional construct?<br>Which institutions and other actors are trusted and which are not?<br>How important is trust in actors, in institutions and in general? |

*Organization of the public debate* - For each organized debate the theme, the aim, the way the debate is organized, the kind of communication, and the means of public participation used are described. For this purpose, the list of types of public participation mechanisms described by Rowe and Frewer (2004) (i.e., referendum, public hearing, public opinion survey, negotiated rule making, consensus conference, citizen's jury or panel, citizen advisory committee, focus group) was used.

*Public perceptions and attitudes* - If available, a description of the perceptions and attitudes of the public regarding the theme of the public debate will be given.

*Actors and roles* – The roles of both the public and scientists are described. The roles of the general public may vary from a passive public (possibly attentive or interested, see Miller, 1993) to an active public in various roles (Logan, 1999; Wynne, 1991). The roles of scientists may vary from that of experts with their expert knowledge to one where scientists contribute to knowledge at the same level as the other actors.

*Level of participation* - According to Arnstein (1969), the level of citizen power tells something about the level of participation (cf. Jacobs et al., 2003; Rowe & Frewer, 2004). In her *ladder of participation,* Arnstein distinguished eight levels of participation varying from non participation to full decision-making power. Where applicable, arguments for giving influence are described as well (Jacobs et al., 2003).

*Level of institutionalization* – Another way to analyze the influence and the power of participants is by describing the level of institutionalization for public participatory events, as has been described by Einsiedel and Wambui (2006). Furthermore, analysis were carried out of policy statements or laws that followed upon the public debate, the structural response to or support for the public debate, the resource base for the public debate (e.g., whether or not it is paid for by public funds), and the initiative for organizing the public debate (e.g., by which organizations).

*Communication process* – Carey (1989) distinguished two conceptions of communication, namely: one as a one-way, top-down flow of information, and another one as a dialogue with two-way flow of information (Rowan, 1994).

*Scientific knowledge* - Knowledge may either be considered as factual knowledge (sound science, cf. Miller, 1993), which is fixed and certain, or as existing of more types of knowledge, functioning as one among several kinds of knowledge (Wynne, 1991).

*Trust* – Trust is either taken for granted and then mostly considered as a one-dimensional construct (Von Grote & Dierkes, 2001) or it is seen as a multi-dimensional construct. And, this second view is gradually replacing the concept of a knowledge deficit as one of the explanations of the controversy regarding biotechnology and genomics (Hansen, 2005).

## 4.3 Results

In this section, the five[1] debates on biotechnology that were organized in the Netherlands are described in detail, following the above-mentioned frame of analysis. Contextual information about the debates is given, such as dates, themes, aims, and means. Where

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[1] The literature is not clear about the number of debates that has been organized. Some authors claimed that the GM Food debate was the sixth debate (Te Molder & Gutteling, 2003, p.120; Hanssen et al., 2001). However, one of the debates (i.e., that was held in 1996) was not about biotechnological but about environmental issues (Ministerie VWS, 1999). This debate was excluded from the analysis. Neither were the so-called broad societal debates on issues such as nuclear energy and the environment analyzed (see also Chapter 1).

applicable, the publics' attitudes and perceptions are described. Then, the publics' and scientists' roles in the debates and the level of participation and institutionalization are portrayed. Subsequently, issues concerning the communication process, knowledge and trust are described. Finally, the main findings of the analysis will be summarized.

### *4.3.1 Five public debates on biotechnology: contextual information and public's attitudes*

In 1993, the first Dutch public debate on issues related to biotechnology was organized, titled 'Genetic modification of animals, should it be allowed'[2] (see Table 4.2 for an overview of the results). The goals of the debate were (1) to identify the questions, the worries, and the expectations that the general lay public has with respect to biotechnology, (2) to put these on the agenda in the discussions about the possibility of adopting modern biotechnology in this country, and (3) to ensure that the lay public is given a change to participate in the debate.[3] Set up as a consensus conference, it followed the example of the Danish consensus conferences[4].

In 1995, the second debate took place, addressing 'Human Genetic Screening Research'.[5] The immediate reason for organizing this debate was the fact that Dutch bull 'Herman' had the human gene lactoferrin implanted. This raised the issue of animal welfare, i.e., whether the use of animals for biotechnological profits should be allowed.[6] The aims of the debate were to provide the general public with information on the issue, to raise awareness about it and to encourage the development of public opinion on the societal implications and the ethical issues involved in screening research.[7] Again, a consensus conference was organized, in conjunction with workshops with experts and consumer associations.[8]

In 1998 and 1999, a debate on 'Clones and Cloning' was held. The announcement of the birth of Dolly the sheep, cloned from an adult animal, was the reason for organizing this debate.[9] As was the case in the preceding debates, the goals were to inform the general public and to encourage the development of public opinion, based on rational arguments, and, consequently, to identify where society draws the line.[10] The organizational set-up of this debate included more means than was the case in the other two debates. A citizen's

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[2] Stichting PWT (1993).

[3] Stichting PWT (1993, p. 3).

[4] Hamstra (1995).

[5] Hamstra (1995); Mayer, De Vries and Geurts (1995).

[6] Integrale Beleidsnota Biotechnologie (2002), see Appendix 2.

[7] Ministerie VWS (1999, p. 31).

[8] Hamstra (1995); Mayer et al. (1995).

[9] See, for example: Hoorzitting over klonen en kloneren. Rathenau Special (1998); Cloning, surrounded by concern (1999); Het Burgerpanel Kloneren zoekt naar Grenzen. Slotverklaring (1999).

[10] Hoorzitting over klonen en kloneren. Rathenau Special (1998).

panel was set up, consisting of twenty members of the general public. In addition to their own meetings (ten sessions), they followed all other activities organized during the debate, in order to come up with a citizens' opinion. First of all, these other events consisted of an agenda-setting hearing in which experts were questioned. Next, five public debates on issues concerning cloning, a public survey, four regional meetings, and a final meeting were organized. A book was also published, aimed at informing the general public about cloning and the potential risks and benefits of it.[11]

In 1999 and 2000, this debate was followed by a debate on 'Xenotransplantation'.[12] Its goal was to inform the public, to enrich the opinions held by citizens, to discuss the theme in society, and to provide a clear overview of the opinions put forward in the public debate, while a moratorium on xenotransplantation was in effect.[13] The debate involved a kick-off meeting, public meetings, and two websites. One of these websites gave the public the opportunity to get informed and to respond to this information. Additionally, a third website, for high school students and entitled 'BioDebat', was aimed at improving the information gathering skills of pupils. Furthermore, a theatre performance took place and a survey was conducted on the perceptions of organ donation, which included items on xenotransplantation. There was a lot of information available in the form of advertisements, cartoons, and so on, and the debate was concluded with a final meeting.[14]

A year later, in 2001, the last public debate related to biotechnology was held, dealing with 'GM Food'.[15] The rationale for this debate differed from that of the previous debates: its purpose was to inform the general public about food genomics, to register public opinion on this subject, and to investigate which conditions the public deemed necessary for allowing food genomics.[16] This debate was the most extensive of the five debates, as the largest variety of communication and participation mechanisms were offered. It started with a public meeting and a public hearing. Regional public meetings were organized in collaboration with schools and civil organizations, in which the public could discuss the issue with the help of a 'toolbox'.[17] A theatre show was developed, which

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[11] Kloneren met zorg omgeven (1999).

[12] Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie (2001); for an English summary of the report, see also Xenotransplantation. Is and Should It Be Possible? Final Report in Respect of the Public Debate on Xenotransplantation (2001).

[13] Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie (2001).

[14] Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie (2001, p. 12, 13).

[15] Eten en Genen. Een publiek debat over biotechnologie en voedsel (2002). See also Hanssen et al. (2001).

[16] Eten en Genen. Een publiek debat over biotechnologie en voedsel (2002).

[17] The toolbox contained a reader with general information and background articles about gene technology and its social implications, a leaflet, a document about the examples discussed during the GM food debate, a video entitled 'Smaakt biotech naar meer?', guidelines with practical recommendations and intrinsic recommendations

was performed at schools and for other groups in society. For the general public, websites and information materials were developed, and three surveys were conducted during and after the debate to explore public opinion on the matter.[18]

During the debates, the publics' attitudes towards the specific themes of the debates varied, but these attitudes were not always measured. In the first two debates – dealing with transgenic animals and human genetic screening, respectively – the attitudes of the general public towards the themes were supposed to be influenced positively by knowledge of these themes, but no surveys were conducted to poll for the opinions of the Dutch general public.[19] Information on the attitudes of the public was gathered in the subsequent debates on cloning and xenotransplantation by means of a representative survey. Objections against cloning were widely shared among the population, while attitudes towards xenotransplantation were more nuanced: half of the respondents considered the latter application undesirable (52%), while the other half deemed it acceptable, but only if one could expect a reasonable quality of life (48%). All respondents considered xenotransplantation to be the least desirable option.[20] During and after the debate on GM food, in the three surveys that were conducted, respondents' attitudes showed a dichotomous distribution, with 43% of the respondents opposing GM food, and 26% unconditionally in favour of it. If certain conditions would be met, such as demonstrable benefits, and strict conditions for the products, the approval rate would increase to 38%.[21]

So far, five nationally organized public debates have been held in the Netherlands that were directly related to biotechnology. After 2001, some surveys have been held (e.g., on genomics), but no other national debates on issues related to biotechnology that enabled public participation, have been organized. Two other public debates that were not directly related to biotechnology took place: a so-called 'broad societal debate' on nuclear energy, which was organized between 1981 and 1983, and, in 1996, a debate was held on environmental development was held. Neither of these debates has been included in the current analysis.[22]

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about the organization of a public meeting, and an evaluation form (Eten en Genen. Een publiek debat over biotechnologie en voedsel, 2002).

[18] Eten en Genen. Een publiek debat over biotechnologie en voedsel (2002). Gutteling, Van der Veer and Hanssen (2001a); Gutteling, Van der Veer and Hanssen (2001b).

[19] However, Mayer et al. (1995, p. 109) conducted a study aimed at the evaluation of the effects of participation in the consensus conference on human genetics research. This was a quasi-experimental pre-test/post-test design with six different panels with different degrees of participation.

[20] Klonen en kloneren, wat u ervan vindt (1999); Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie (2001, p. 84-88); Hanning and Aarts (2001).

[21] Gutteling et al. (2001a); Gutteling et al. (2001b).

[22] Integrale Beleidsnota Biotechnologie (2002), see Appendix 2; Te Molder and Gutteling (2003).

**Table 4.2: Dutch public debates on biotechnology: contextual information**

| Debate on: | Transgenic animals | Human genetic screening | Cloning | Xenotransplantation | GM food |
|---|---|---|---|---|---|
| *Year* | 1993 | 1995 | 1998/1999 | 1999/2000 | 2001 |
| *Goals* | To have questions, worries, expectations of the general lay public put on the agenda in the discussion on the potential of modern biotechnology | To discuss social and ethical issues with experts, to initiate a broader public discussion, and to set the agenda | To inform about the potential of the use of clones. To enable citizens to express their opinions on cloning technology | To discuss the issue in society during the two years that a the moratorium on xeno-transplantation was in effect | To inform and consult the general public. To clarify the conditions under which biotechnology is acceptable. The if-question is not part of the debate |
| *Initiators and main organisers* | Initiated by the organizing institutions, i.e., NOTA, PWT and SWOKA. | Initiated by intermediary organizations (Platform for Science and Ethics). Organized by NOTA, PWT, SWOKA and some other organizations | Initiated by the Minister of Health, Welfare and Sport. Organizer is the Rathenau Institute, in collaboration with other organizations | Initiated by the Minister of Health, Welfare and Sport. Organizer is the Dutch Consumer and Biotechnology Foundation | Initiatiated by Parliament on behalf of the Committee on Biotechnology and Food organized by Stichting Weten and several other organizations |
| *Communication and public participation means* | > Several publications on genetic modification of animals<br>> Consensus conference with lay panel and experts | > Interactive meetings for experts and six workshops for informed stakeholders<br>> Consensus conference with lay panel and experts | > Agenda-setting Public hearing<br>> Citizen's panel<br>> Five Public Debates on issues concerning cloning<br>> Final meeting<br>> Four regional debates<br>> Public opinion survey on the perceptions of cloning among the Dutch public<br>> Report to Parliament | > Kick-off meeting<br>> Public meetings<br>> Websites > Internet Debate BioDebat for high school pupils with forum and website on xeno<br>> Theatre performance<br>> Survey on the public perceptions of xeno and organ donation (including 4 focus groups)<br>> Information material (advertisements, free publicity, cartoons)<br>> Final meeting | > Kick-off meeting<br>> Public hearing<br>> Regional public meetings in collaboration with civil organizations.<br>> Toolbox including a video<br>> Theatre performance<br>> Three surveys polled the Dutch public about GM Food<br>> Questions to the public in the media<br>> Websites<br>> Information material (e.g., leaflets, advertisements) |

**(Table continues)**

**Table 4.2 (continued): Dutch public debates on biotechnology: contextual information**

| **Debate on:** | **Transgenic animals** | **Human genetic screening** | **Cloning** | **Xenotrans-plantation** | **GM food** |
|---|---|---|---|---|---|
| *Publics' attitudes towards and perceptions of the theme of the debate* | No national survey conducted | No national survey was conducted, but an evaluation study was carried out<br>The lay panel is less fearful, more supportive of, and more informed about the topic<br>More trust in policy and technology by active participants > depending on stage technology | A national survey found that objections were widely shared among the population | A national survey found that half of the population (52%) regarded the application as undesirable; the other half (48%) regarded it acceptable if one could expect a reasonable quality of life<br>Also: xeno as the least desirable solution<br>Ambivalent attitudes towards the progress being made by science desirable and transcending boundaries | Three surveys (two during the debate, one afterwards) showed that 43% was against, and 26% in favour of GM Food. When its use is clear, under certain conditions, higher percentage would support GM food. There is a dichotomy between attitudes towards gene technology those towards food |

### 4.3.2 *Actors and roles in the debates and influence on decision making*

Relatively few citizens participated in the first two debates – addressing transgenic animals and human genetic screening, respectively – since activities were mainly organized around the two consensus conferences, in conjunction with a lay panel of about fifteen members (see Table 4.3). The second debate, which focused on human genetics research, also included workshops with experts and consumer organizations. In both debates, panel members did have an agenda-setting role with regard to the issues discussed in the debate, while other citizens could attend the conference as well. Scientists[23] took part in roles as experts and advisors. The lay public was considered to be uninformed and the debate was organized to examine how this public would react when it was informed by experts. These two debates demonstrated that, once lay people were informed, they were able to discuss the matter with experts.[24]

Considered in the international context, these two public debates took place relatively early. Both debates followed the example of the Danish consensus conference model in which lay people set the agenda for discussion, but with some modifications. In Denmark the consensus conferences were a governmental initiative, while in the Netherlands

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[23] Eleven scientists were involved in the first debate and sixteen in the second one. See Integrale Nota Biotechnologie (2001, p. 79).

[24] Hamstra (1993).

it was instead various social organizations that took the initiative. For example, in the case of transgenic animals, the following organizations were involved: the Dutch Foundation for Public Information on Science, Technology and the Humanities (PWT), the Dutch Office for Technology Assessment (NOTA), and the SWOKA Institute for Consumer Research.[25] The first two institutions were independent organizations, although they were funded by the government. And the third was a commercial institute. In the case of the debate on human genetics screening, the Platform for Science and Ethics was involved in initiating the public debate, while NOTA and PWT, together with some NGOs, organized it.[26] In both debates, the government had a rather passive role, but it was invited to contribute as well and it supported the debate with some funding. The results of the consensus conferences were reported back to the parliament, but the public had no influence on the political decision-making process. In the transgenic animal debate, the panel was doubtful about its own influence, since the debate attracted rather limited (media) attention and as the policy makers finalized the decision-making process shortly before the conference was held.[27]

In 1998/1999 and 1999/2000, two debates were held, one of which dealt with cloning and another addressed xenotransplantation. Both debates were organized on behalf of the Minister of Health, Welfare and Sport.[28] The debates consisted of a series of instruments in which the public was involved in various ways. This involvement ranged from a passive role for the public when information was gathered about the perceptions of the public in the surveys,[29] to a more active role in the public meetings.[30] The role of the citizen's panel on cloning was not as active as expected. The panel's task was to produce the final conclusion, but the panel mainly fulfilled a listeners' role. This might be related to the fact that the panel did not set the agenda for the most important issues in the debate, a task that was instead carried out by some policy makers and scientists.[31] Scientists advised the meetings in their role as experts.

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[25] Glasmeijer (1995); Hamstra (1995).

[26] Glasmeijer (1995); Mayer et al. (1995).

[27] Ministerie van VWS (1999).

[28] Hoorzitting over klonen en kloneren. Rathenau Special (1998); Stichting Consument en Biotechnologie (2001).

[29] 847 Respondents filled out the survey on cloning (Klonen en kloneren. Wat u ervan vindt, 1999, p. 4).

[30] It is not known how many citizens participated in the public meetings on cloning. The kick-off meeting on xenotransplantation was attended by approximately 170 participants with various backgrounds as politicians, experts, persons involved, representatives of NGOs, attendants of public discussions. The political debate on cloning was attended by five members of the Parliament. The Final meeting on cloning was attended by approximately 120 participants, again with various backgrounds (Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie, 2001, p. 49-54).

[31] Ministerie van VWS (1999, p. 35).

Both debates were organized in response to the unease in society caused by Herman the bull and Dolly the sheep, respectively. Policy makers and parliament considered publics opinion as valuable and advocated for it to be taken into account.[32] The Rathenau Institute (formerly NOTA) and the Dutch Consumer and Biotechnology Foundation organized both debates in collaboration with other organizations, while the Minister of Health, Welfare and Sport provided the funding. The results of the public consultations were reported back to the parliament and taken into account as advice in the political decision-making process on the issue.[33]

In 2000, the government published a report on biotechnology,[34] which, in 2001, led to the establishment of two committees: a Provisional Committee on Biotechnology, established by parliament, and the Committee Biotechnology and Food, established by the Minister of Agriculture. The latter organized the public debate on GM food. Amongst the debates that were held until this time, the debate on GM food was the most extensive, in terms of the range of activities and the public participation mechanisms that were involved.[35] Members of the public were involved in the debate in three ways: as a panel of 150 persons with an active role, as interested citizens in public meetings[36] organized at the local level, and as the public at large whose perceptions about and attitudes towards GM food were measured in two surveys.[37] However, the active role of the panel was downplayed, since members could not actively invite scientists to provide information, or ask questions during the public hearing.[38] Scientists took part in the debate in their roles as experts and advisors.[39] The debate was requested by parliament, and funding was provided by several Ministries.[40] The Committee Biotechnology and Food was responsible for the final report, with several other organizations contributing to the realization of the debate. The final report was sent to the Minister, who reported to the Dutch parliament. Unfortunately the parliamentary debate on the issue had been scheduled before the report had been completed, despite the fact that, at the last moment, parliament postponed the debate

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[32] Ministerie van VWS (1999, p. 30); Kloneren met zorg omgeven. Bericht aan het parlement (1999).

[33] Stichting Consument en Biotechnologie (2001); Ministerie van VWS (1999).

[34] Integrale Nota Biotechnologie (2000).

[35] Hanssen et al. (2001).

[36] About fifty organizations participated by organizing a local discussion for their members or for other interested citizens. For this purpose, a toolkit was developed with, amongst other things, a manual, a videotape, and a reader with background information (Hanssen et al. 2001, p. 23). Besides that, at about 170 schools the theatre performance ‘With or Without’ was performed, followed by a debate about GM food, and an opportunity to contribute to the ‘With or Without’ website (Hanssen et al., 2001, p.14).

[37] Gutteling et al. (2001a); Gutteling et al. (2001b). In the first survey, 1019 respondents participated, while in the second one, 1292 respondents took part.

[38] Hanssen et al. (2001, p. 49).

[39] Hanssen et al. (2001).

[40] Hanssen et al. (2001).

so that the findings of the public debate could still be taken into account, the report was regarded as having no influence on the decision-making process.[41]

**Table 4.3: Dutch public debates: actors and roles, level of participation and institutionalization**

| Debate on: | Transgenic animals | Human genetic screening | Cloning | Xenotransplantation | GM food |
|---|---|---|---|---|---|
| *Actors involved* | Public<br>> Lay panel (15) and interested public (few attending)<br>Scientists (11)<br>Journalists<br>Government | Public<br>> Lay panel (15) and interested public (few attending)<br>Scientists (16)<br>Journalists<br>Government<br>Industry | Public<br>> active public in citizen's panel (20) and attending the debates<br>> passive public in survey;<br>> no general public involved, but only some members of the public for some activities<br>Government<br>Scientists | Public<br>> Individuals and high school students<br>Experts<br>Media<br>Government, Policy makers, politicians<br>Professional organizations<br>Public organizations, Social organizations | Public<br>> 150-member panel, active role; 50 organizations at local public meetings, including high school students, general public, Scientists, Media Policy makers, Government, NGO's.<br>> 15 NGO's declare to have no trust in debate. This could lead to the public opinion that no real debate on content and transparency in the decision-making process is possible. |
| *Level of participation*<br>*> power of public*<br>*> influence*<br>*> arguments* | Consultation of the public<br>> for advice to parliament on own initiative<br>> to put opinions, worries general public on agenda<br>Low level of influence<br>> debate is experiment in decision making policy<br>> To make clear what questions lay public has | Consultation of the public<br>> for advice to parliament on own initiative<br>Success products dependent on public support<br>Not necessarily taken up by political parties or special-interest groups<br>Organized to empower people.<br>Influence low: hope that Parliament would recognize the importance of the initiative and would listen to the outcomes | Consultation of the public, placation, but also non-participation in survey<br>> Advice to parliament on initiative Minister<br>> listening to people's opinion is important<br>> triggered by responses to sheep Dolly | Advice to parliament on initiative Minister<br>> taken into account, to gather palette on opinions<br>> Intended to involve the public<br>> Generating support for policy and trust in policy makers. Is important in a democracy | Advice to parliament<br>> no influence on decision making<br>> discussion in parliament postponed to take final report of the debate into account<br>> no agenda setting function |

**(Table continues)**

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[41] Hanssen et al. (2001).

**Table 4.3 (continued): Dutch public debates: actors and roles, level of participation and institutionalization**

| Debate on: | Transgenic animals | Human genetic screening | Cloning | Xenotransplantation | GM food |
|---|---|---|---|---|---|
| *Level of institutionalization*<br>- *law*<br>- *support*<br>- *funding* | Reported to parliament by NOTA, no influence on policy making<br>Funded by the organizing organizations (e.g. NOTA, PWT, SWOKA), plus two Ministries contributed: the Ministry of Agriculture, and the Ministry of Science and Education | Not implemented by law or other wise, low level of influence on policy making<br>Funded by intermediary organizations (Platform for Science and Ethics) and Ministry of Science and Education | Outcome is taken into account, not a direct policy statement is taken on basis of this debate<br>Debate is funded by the Minister of Health, Welfare and Sport | Opinions involved in future policy<br>Not structurally supported, but this debate is asked for<br>Debate is single activity<br>Subsidized by the Ministry of Health, Welfare and Sport | Outcome is not directly taken into account in policy making<br>Competition between committees<br>Responsibility of the Committee on Biotechnology and Food.<br>Funded by several Ministries |

### 4.3.3 *The communication process, including the role of knowledge and trust*

In this section, the way communication, knowledge and trust were seen in the debates is analyzed (see Table 4.4). In the first two debates – on transgenic animals and human genetics research, respectively – the communication process was a two-way process, with direct interaction aimed towards listening and open dialogue. Members of the public could set the agenda.[42] With regard to the debate on transgenic animals, in one of the closing remarks surprise was expressed for the high level of knowledge of the panel members.[43] With respect to the human genetics research debate, results from an evaluation study showed that the lay panel members and the audience became significantly more informed in the course of the debate; while the control groups showed no, or very little, change in their knowledge about the issue.[44] Although in the first two debates trust was not a big issue, the organizers of the debates on transgenic animals assumed that trust could be increased by involving citizens in the decision-making process. However, according to the Ministry of Health, Welfare and Sport (Ministerie van VWS), the panel members' trust did not increase since the political decisions were mostly taken shortly before the conference took place.[45] For the debate on human genetics research it was also believed that participation by the public would increase its trust in the government in

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[42] Hamstra (1995).

[43] Genetische modificatie van dieren, mag dat? Verslag van het publiek debat (1993, p. 84); Hamstra (1993, p. 88).

[44] Mayer et al. (1995, p.122).

[45] Ministerie VWS (1999, p. 29, 30).

general and in the technology in particular, and, this time around, this assumption was indeed borne out by the facts.[46]

In the third and fourth debates – on cloning and xenotransplantation, respectively – the communication process consisted of one-way and, more often, two-way processes. The two-way communication process involved listening and open dialogue. For example, the citizens' panel in the cloning debate could also ask scientists for clarification and specification and especially the public hearing in the cloning debate was meant for agenda-setting by the public,[47] while the surveys were a one-way, bottom-up process focused on the receivers' opinion. The websites in the xenotransplantation debate were a one-way, top-down process, aimed at informing, but it was also possible to join the discussion, in which case the site served as a two-way communication process. The kick-off meeting, the other public meetings and the theatre performance were all two-way communication processes. The information campaign was meant to inform, and, hence, it was characterized by one-way communication processes.[48]

The Minister of Health, Welfare and Sport Citizens stressed that citizens need more information and deliberative discussions about cloning. She emphasized that it was important to take away societal unrest, and therefore, it was a matted of major concern to ensure that the information provided was reliable and of a high quality.[49] However, in the debate on cloning, knowledge was conceived of as something broader than mere scientific knowledge. In the cloning debate, the citizen's panel argued that emotional feelings were not merely 'gut feelings'. They believed that emotional arguments were important counsellors for people and, hence, that they should be taken seriously.[50] In the cloning debate, knowledge was thus viewed as inextricably embedded in people's other feelings. According to the panel members, emotions played an essential role, but others claimed that emotions sometimes dominated the debate. The panel members formulated three observations. Firstly, the question whether or not emotions did dominate the debate had not yet been settled. Secondly, that there was no consensus about facts and emotions. Thirdly, that not only opponents of cloning, but also its advocates used emotions.[51] This discussion showed that scientific facts and other knowledge about cloning were not always strictly separated from each other. Furthermore, in the debate on xenotransplantation the organizing committee concluded that knowledge was embedded in peoples' feelings and

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[46] Ministerie VWS (1999, p. 32).

[47] However, afterwards the Ministry of VWS concluded that agenda-setting for the most important points was done by some policy makers and scientists (Ministerie VWS, 1999, p. 35).

[48] Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie (2001).

[49] Hoorzitting over klonen en kloneren. Rathenau Special (1998, p. 3).

[50] Cloning: surrounded by concern. Conclusions of the societal debate. Report to the parliament (1999, p. 6).

[51] Swierstra (2000, p.122, 123).

outlook on life. Therefore, as communication processes are not only about informing other, but also about listening to each other, they should not be limited to one-way processes.[52]

In the cloning debate, trust was an issue of concern, since the panel emphasized support for and trust in scientists as being important in a democracy. According to the panel, nobodies' view is unbiased. The panel considered the debate a valuable step towards improvement of the relationship between science and society.[53] In the debate on xenotransplantation, the role of trust was emphasized more explicitly. According to the final report on the xenotransplantation debate, trust in policy makers and public support for decisions are crucial in a democratic society – especially when it concerns the introduction of new technologies such as biotechnology and information technology – and public debates can contribute to building trust and getting public support.[54]

In the debate on GM food, the communication process existed of a combination of two-way communication in the public meetings and debates, one-way, top-down communication on the website, and one-way, bottom-up communication in the survey. In the public hearing, the panel members were not allowed to ask questions; only committee members could do that. Therefore, the public hearing was a one-way process of information and persuasion, rather than a dialectic, two-way process.[55] With regard to the website, the general public was able to ask questions and to react to information.

An analysis of these messages left behind on the website showed that there were hardly any responses to the contributions placed on the website. The website was mainly used as a source of information, and, therefore, it essentially represents a one-way information process.[56]

In the GM food debate, knowledge was mainly regarded as a means to inform the public. The committee concluded that decreasing the public's knowledge deficits was important for instilling sound judgement about biotechnology on the part of the public.[57] At the same time, the results from the surveys showed that respondents held the opinion that the information provided was insufficient.[58] The survey results revealed that trust in scientists and in policy makers or the government was considered important, especially in connection to the big difference in knowledge between experts and the lay public.

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[52] Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie (2001, p. 3).

[53] Het burgerpanel Kloneren zoekt naar grenzen. Slotverklaring (1999).

[54] Xenotransplantatie, kán dat? Eindrapport van het publiek debat xenotransplantatie (2001, p. 4).

[55] Hanssen et al. (2001, p. 49).

[56] Hanssen et al. (2001, p. 50).

[57] Eten & genen. Een publiek debat over biotechnologie & voedsel (2002, p. 20).

[58] Gutteling et al. (2001a); Gutteling et al. (2001b); Hanssen et al. (2001).

**Table 4.4: Dutch public debates: attitudes and perceptions, knowledge, communication and trust**

| Debate on: | Transgenic animals | Human genetic screening | Cloning | Xenotransplantation | GM food |
|---|---|---|---|---|---|
| *Communication process*<br>- *flow*<br>- *content* | Bottom up and top down<br>> listening and open dialogue | One-way and two-way communication<br>> listening and open dialogue | One-way communication bottom-up<br>> survey on perception public. Two-way communication<br>> public hearing; public meetings<br><br>Mix of technical information and receivers' opinion, and listening and open dialogue | Two-way process, but also informing public; One-way communication bottom-up<br>> survey on perception public; website; Two-way communication<br>> public meetings, theatre performance (incl. discussion)<br>One-way top down<br>> website, information material<br>> Transparency, mutual respect and communication | One-way communication bottom-up<br>> Two way communication in debates<br>One-way top-down<br>> informing public via website |
| *Knowledge*<br>- *sound science*<br>- *kinds of knowledge* | Lay public is uninformed, how will this public react when it is informed by experts<br>Lay people are able to discuss matters with experts | Knowledge gap between scientists and the general public. Knowledge is contextual | Emotional arguments are not merely gut feelings. Such arguments are important counsellors for people, and that is why they should be taken seriously > kinds of knowledge | Embedded knowledge: 'people's feeling and outlook on life also from part of any communication in which they are involved' | To inform |
| *Trust*<br>- *perception trust*<br>- *in whom and what* | Not a big issue<br>Trust could be increased by involving citizen in decision making process. In this debate trust has not increased<br>Members panel: 6 more negative, 5 more positive | Participation in debate increases trust in technology and government | Needed in a democracy | Generating support for policy and trust in policy makers which is important in a democracy. Support and trust are crucial. Public debate is valuable step in direction of an structural improvement of the relationship between science, technology and society | More uncertainty and risk involved<br>Trust is more complex<br>Transparency on risks and uncertainties is essential<br>Debate should be a continuous process<br>Building trust should be an issue |

The Committee on Biotechnology and Food concluded that, if the public trusts government, industry and regulatory bodies, acceptance of GM food products will be higher.[59] The Committee also concluded that public support for new technologies was essential. Trust in the government had decreased, and, therefore, since the government sets conditions for industry and science, restoring the trust in government was crucial.[60] Furthermore, trust became an issue when 15 NGOs explicitly and publicly abandoned their trust in the public debate and, hence, decided that they would no longer participate in the public debate on GM food.[61] More in general, the researchers that evaluated this public debate concluded that trust was an important issue for the general public, and that is was more complex than previously believed to be the case, and stretched further than restoring trust in the government and in the other actors involved in the technology. Trust required openness about potential risks involved in the technology and transparency in the decision-making process. Therefore, dialogue should become a continuous process for all actors, including the general public.[62]

### *4.3.4 Summary of the main results*

To sum up, the five organized public debates in the Netherlands covered a variety of issues, and, over time, they were characterized by an increasing variety in the means of communication and public participation. The goals of the debates varied from putting public concerns on the political agenda to providing the public with information, encouraging or enriching the development of a public opinion about the various issues at stake, finding out where the limits of social acceptability are located, and investigating conditions for acceptance.

Public perceptions and attitudes towards biotechnology varied considerably, depending on the specific issue that was at stake. The first two debates were not accompanied by national surveys, but the few participants in these debates said to be influenced positively by the knowledge they gained about the issues. This anecdotal evidence on participants' attitudes can of course not be compared to the public's attitudes in the systematic surveys on cloning, xenotransplantation, and GM food. These surveys showed that, in 1998, the Dutch public was opposed to cloning, but that in 1999 half of the Dutch public considered xenotransplantation acceptable, be it that they considered it the least desirable solution to the shortage of donor organs. The surveys on GM food in 2001 revealed that proponents and opponents of GM food were about equally distributed. Under certain circumstances, such as demonstrable benefits and strict conditions for the products, a higher percentage of the respondents favoured GM food.

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[59] Eten & genen. Een publiek debat over biotechnologie & voedsel (2002, p. 3).

[60] Eten & genen. Een publiek debat over biotechnologie & voedsel (2002, p. 4).

[61] Hanssen et al (2001, p. 49).

[62] Hanssen et al. (2001, p. 54).

The analysis of the roles of the public and scientists led to two main conclusions. The first concerns the roles of the public and scientists, and the second relates to the number of people that participated in the debates. In all debates, scientists were involved in their role as experts, while the general public was involved in a variety of roles. It played a role as an active public and an interested public that could join the various meetings, but in several cases this active role (e.g., as panel member) was downplayed by the organizers, since the public was only allowed to fulfil the role of listener. When surveys became part of the organized debates, also a passive public was involved whose opinion was taken into account.

In the first two debates, an exclusive public of about 15 citizens was given a chance to participate, and they actively engaged in formulating the advice for the government. In the debates on cloning and xenotransplantation, slightly more citizens participated, and a survey was conducted to examine the general public's opinions. In the final debate, a group of 150 citizens was actively involved in a panel, and other interested citizens could participate in public meetings on biotechnology. Members of the general public were asked to participate and they stated their opinion in a survey. However, in all cases only a few people actually participated. From the five debates, it has become clear that the public in its role as active public includes rather few individuals.

Regarding the institutional embedding of the debate, the findings showed that the initiative for the first two debates in the Netherlands was taken by several groups in society. Governmental organizations were indirectly involved in the debates. In later debates the Ministry of Health, Welfare and Sport requested the debates and the last debate, on GM food, was requested by parliament. In these latter debates, governmental organizations played a more substantial role.

In all the organized debates, the public was consulted in different ways and for various reasons. However, the reported influence on the decision-making process was very limited in all cases. In the debates on transgenic animals and human genetics research, political influence was minimal, since these debates were initiated by societal rather than by governmental actors. The outcomes were presented to politicians, but they were not taken up by them. The next two debates, on cloning and xenotransplantation, respectively, can be regarded as having had the most influence, since they were initiated by the government and its recommendations were taken into account in the decision-making process. The latest debate, on GM food, was requested by parliament, but, again there was no influence from the general public, since the political decision-making process continued when the debate was still in progress.

In the first two debates, the communication processes involved bottom-up and top-down means of communication, with two-way processes aimed at listening and open dialogue. In later debates, some of the communication with the public was intended as a one-way, bottom-up process, as was the case with the surveys, and some was one-way, top-down, such as the websites, meant to inform the public. Two-way communication processes occurred in the public hearings, in the public meetings and in discussions following the theatre plays, where the purpose was listening and open dialogue. However, in some cases, for example in the public hearings in the debates on cloning and on GM food, in stead of a two-way communication process, a one-way process was strived after, with participants playing the role of listener.

In the debates, scientists were regarded as experts, holding expert knowledge. This scientific knowledge was thought to be important, but from the debates on cloning and xenotransplantation it became clear that scientific knowledge is embedded in other kinds of knowledge. In the debate on cloning, this other kind of knowledge was called 'emotional arguments'. In the debates on cloning and on xenotransplantation, citizens argued that this other knowledge deserved attention, since people base their opinions on this kind of knowledge as well, and thus perceive knowledge in a different way than scientists do. In contrast, in the latest debate (on GM food), scientific knowledge mainly served to inform the public. In this case, knowledge fulfilled a more expert function with a public that needs to be persuaded as receiver of the information.

In the first of the public debates (dealing with transgenic animals), trust was not yet a big issue. It was thought that trust could easily be increased by involving citizens in the decision-making process, that is, by increasing their knowledge. In the debate on cloning, trust in scientists was mentioned for the first time as the objective, while, in the debate on xenotransplantation, public trust in policy makers was considered important, and public debates were seen as a way to contribute to improving trust. In the GM food debate, trust was regarded more complex than what was previously thought to be the case, and it went beyond the mere restoration of trust in government and other actors. In this latest debate, it was concluded that uncertainty played a larger role, and, thus, more public trust was required. But building trust appeared to be much more complex than what was previously believed, with transparency as one of the influencing factors. Trust became crucial for a democracy in order to function properly, and participation, for example in public debates, was considered a valuable step in the direction of improvement of the relationship between science, technology and society.

### 4.4 Conclusions from the analysis of Dutch public debates on biotechnology

In this section conclusions will be drawn from the findings of this study by answering the research questions. A general conclusion will be drawn and discussed in Chapter 7. To recapitulate, the following research questions were formulated:

*RQ1a: Which roles did the general public and scientists play in Dutch biotechnology debates?*

*RQ1b: Which influence did the general public have on the decision-making process that resulted from the public debates?*

*RQ1c: How were communication processes designed in these public debates?*

*RQ1d: Which roles did knowledge and trust play in these communication processes?*

*The roles of the general public and scientists in the debates*

The findings show that the general public played various roles in the five debates. In most debates there was a role for an active public, but, although strived after, the active public was not participating in large numbers, or was not given the chance to participate in large numbers, since the public participation mechanisms were not suitable for participation by large numbers of individuals. An interested public, and a somewhat larger group, was involved in the later debates. All in all, active participation was restricted to a few people, and these few people were certainly not representative of the Dutch general public as a whole. With regard to the role of scientists, the analysis showed that in all the five debates they were only participating in their role as experts.

*Public influence on the decision-making process*

With regard to the influence of the general public on the political decision-making process, it must be concluded that this influence has been rather insignificant. At best, the recommendations formulated in the public debates were taken into account as advice by parliament in their decision making.

*The design of the communication process*

In the debates a mixture of one-way and two-way communication processes were involved. Consensus conferences were one form of a two-way communication process. Other two-way communication processes took place in the public hearings, in the public meetings and in the debate after the theatre play. Some of the communication means were aimed at letting the public participate, while other were one-way types of communication that were only intended to inform the public. In some cases, such as in the public hearing in the GM debate, the two-way process was downplayed due to limitations for the attending public, and informing was emphasized at the expense of dialogue.

*Knowledge and trust*

Knowledge appeared in the debates in different guises. The first debates were mainly aimed at the dissemination of scientific knowledge. In later debates, scientific knowledge became one among a number of different kinds of knowledge, and, since people base their judgement not on scientific knowledge alone, emotional arguments were deemed deserving the attention as well.

The notion of trust has changed, from a situation where trust was thought to be easily gained by increasing people's knowledge in the first debates, to a situation where it is thought to be quite complex and playing a more important role, in later debates. The analysis demonstrated that public participation increased public trust, which is required for a democracy in order to function properly.

In the following studies a closer look is taken at the publics' relation with science, by examining the relationship between publics and genomics specifically. In Chapter 5 publics in various roles are compared with regard to their considerations about gene research by means of focus group discussions. In Chapter 6, the active and passive participation of various publics in gene research is further investigated.

## *Chapter 5*

# The publics' considerations about gene research
## Results from focus groups discussions

*In this chapter the relationship between publics and science is further explored. Communication, and the way this communication process is perceived by different publics, is part of this relationship. The aim of this chapter is to discuss issues and arguments with respect to the communication on genomics and to identify the similarities and the differences among publics in various roles. Focus group discussions were conducted with members of the inexperienced public, active consumers, patients and genomics experts in the Netherlands. First, data were analyzed and key themes with sub-themes in the communication of genomics research were identified. These key themes were: (1) communication about gene research; and (2) the trust in stakeholders in gene research and the power of these stakeholders. Second, further analysis compared notions held by the inexperienced public, with those of active consumers, patients and experts. The analysis demonstrated that publics in different roles want a different approach of communication, with varying possibilities of participation. However, interest and participation tend to be limited to matters of personal concern. In all cases, basic communication elements, such as transparency and openness have to be fulfilled to gain trust from the public.*

### 5.1 Introduction and research questions

In the previous chapter it has been shown that publics fulfilled various roles – some rather passive and others more active – in the Dutch public debates (Chapter 4). However, these results did not provide insight in what publics themselves, in their various roles, considered important with regard to science issues and the way they are communicated. In this chapter a closer look is taken at the relationship between publics and science by means of investigating the relationship between publics and genomics. The following more specific research question was formulated:

*RQ2: Which considerations do publics in various roles have with respect to (communication aspects of) genomics?*

In public understanding of science literature it was emphasized that concepts such as knowledge, information and communication, and trust and influence play a role in the relationship between publics and science (see Chapter 2). Most studies from this field focus on public perceptions of and attitudes towards science, or genetic engineering, and not on the way these publics perceive the communication, their own and other's roles and influence on decision making and the role of trust. Thus, the main purpose of the following study is to understand more of publics' relationship with science by means of investigating how publics in various roles perceive gene research[1], the communication about gene research, their role and influence on gene research and their trust in gene research. The following empirical research questions were formulated:

RQ2a: *How do publics in various roles consider the communication process about gene research?*
RQ2b: *How do publics in various roles consider their and others' role in and influence on gene research?*
RQ2c: *How do publics in various roles consider trust related to gene research?*

The nature of these research questions, which are aimed at gathering a variation of opinions, could well be investigated by an exploratory study. Therefore, focus group discussions were designed with participants in four different roles, i.e., in the role of inexperienced public, active consumers, patients or experts. In the next section (5.2) the way the focus groups were put together is portrayed in detail. In 5.3 results of the study are presented. Subsequently, an overview of the palette of opinions the participants have discussed is presented, and differences and similarities between groups is focused on. The main results are summarized. In the final paragraph (5.4) conclusions are drawn by pointing out remarkable findings.

## 5.2 Design of the focus group discussions

Focus group discussions were organized and participants were asked for their perceptions on the communication and other related themes regarding gene research. In this chapter, the repertoire of (sub) themes and issues broached by the participants is reported. Interpretation of these perceptions takes place within the context of these public attitudes towards specific examples of gene research.

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[1] Since genomics is a relatively unknown word, in the empirical studies the term gene research was used.

*Process*

A total of eight focus group discussions were conducted that consisted of participants with different backgrounds. Three inexperienced public groups were randomly recruited by a market research company, but all lived in the eastern part of the Netherlands. They were called ‘inexperienced public’, since the research team was unaware of any participant having direct experience with gene research. Other groups could have direct experience with gene research. One active consumer group, two patient groups, and two expert groups were recruited by using the research teams’ personal contacts. Participants in the consumer group were active members of a Dutch consumer association. These active members are knows as the ‘Bondsraad’, which is the membership parliament of the largest Dutch consumer association (‘Consumentenbond’). Participants in the consumer group were recruited through a mail-out to all 100 members of the ‘Bondsraad’. Participants of the two patient groups were members of the Rheumatism patient association, and members of the celiac disease patient association, respectively.[2] Rheumatism patients were approached since some of the medicines rheumatism patients may use are developed with the help of gene technology. These are so-called ‘biologicals’. Celiac disease patients were approached since their patient association is actively involved in genomics research that studies the specific genes involved in causing celiac disease. Members of the two patient associations could participate on a voluntary basis after a message was placed on the website of the patient association and an active member of the patient associations’ committee was asked for assistance. Finally, experts were defined as participants affiliated with a wide variety of organizations. Due to the functions they fulfilled in these organizations, they were expected to have experience with gene research or gene technology products. They were asked to participate and were assigned to either of the two groups based on their experience with either medical or food issues. Representatives came from governmental organizations, the political field and political organizations, industry, lobby groups, pressure groups, research organizations, and media organizations. Both groups were designed to sample a wide variety of backgrounds.

**Table 5.1: Overview of number of participants per group**

| | *Inexperienced public* | | | *Consumers* | *Patients* | | *Experts* | | |
|---|---|---|---|---|---|---|---|---|---|
| **Group** | **1** | **2** | **3** | **Active consumers** | **Rheuma-tism** | **Celiac disease** | **Medical** | **Food** | **Total** |
| Number of participants | 10 | 9 | 9 | 7 | 10 | 10 | 9 | 6 | 70 |
| *Male* | 5 | 7 | 4 | 4 | 4 | 2 | 9 | 3 | 38 (54%) |
| *Female* | 5 | 2 | 5 | 3 | 6 | 8 | 0 | 3 | 32 (46%) |

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[2] Celiac disease is an intolerance for gluten. It is a disease that cannot be treated with medicines, but patients need to keep a strict gluten-free diet. Grain, an additive in many products, contains gluten.

All in all, 70 participants took part in eight focus groups (see Table 5.1). For all the groups, 8 to 10 participants were recruited, while 6 to 10 people actually showed up. The mean age of the participants was 54.8 years (SD = 13.0), with a range of 20 to 83 years. The participants consisted of 32 females (46%) and 38 males (54%).

The focus group discussions were guided by two moderators. The moderator of the inexperienced public groups was experienced in conducting focus groups. The moderator of the consumer group, the patient groups, and the expert groups was experienced in conducting focus groups and had relevant knowledge of genomics. To enhance internal consistency, in all of the eight focus groups the same observer, co-responsible for analysis, took notes (cf. Kidd & Parshall, 2000). The focus groups discussions were both video and audio taped to allow transcription of the discussions afterwards. The discussions lasted approximately two hours each. At the end of each discussion a short debriefing took place. Following the discussion, each participant completed a background questionnaire. Finally, the participants had their travel expenses reimbursed and they received a fee of 30 Euros for attendance.

The discussions were verbally transcribed and then analyzed in steps. First, the data were divided into separate, individual quotations: the words uttered from the time one participant began speaking until the next participant started. Next, a classification scheme was developed, based on a reading of the transcripts. A combination of both broad and fine-grained coding took place. First, major themes were coded, followed by the coding of sub-themes and underlying issues or arguments. For each group, the variety of issues was analyzed, and differences and similarities between the groups were examined. Finally, broader patterns that emerged across group discussions were identified. Interpretation was based on a contextual analysis rather than on frequencies. According to Kidd and Parshall (2000), following this entire iterative process contributes to the validity of the analysis. For the analysis the program Atlas.ti version 5.0 was used.

*Protocol for the focus group discussions*

During the focus group discussions, the moderators used a protocol to ensure as much as possible that the same procedure was followed, and to guarantee equality of data, since differences in moderator experience and interviewing style might affect the flow, texture, and content of the discussions (Kidd & Prashall, 2000). The protocol was written in Dutch (see Appendix 2), and was based on theoretical assumptions and on twelve interviews conducted (from October 2005 until February 2006) with experts in the Dutch genomics field (see Appendix 3). The protocol was reviewed by two experts. After the first focus group, the protocol was reviewed and some minor revisions were made. For example, the research team now asked first about the participants' associations with gene research, since in the first group (the rheumatism patients), the participants themselves spontaneously pointed to these while discussing the themes.

The protocol consisted of two parts. In the first part, which lasted about three quarters of an hour, the research team asked participants to give their free associations of the term 'gene research', and, subsequently, they discussed three different examples of gene research (see Table 5.2). In the second part, which lasted approximately one hour and fifteen minutes, participants were asked to discuss several themes that delved more deeply into the communication surrounding gene research, the role different actors play in this communication process and the role of trust and power.

The three different examples each group of participants discussed in the first part of the discussion depended on the specific focus or background of the participants, except in the inexperienced public groups. One of the inexperienced public groups discussed medical examples, another discussed food examples, and a third group discussed a mix of both. All examples formulated for the discussion were based on recent publications in the mass media in the Netherlands, so these might be familiar to the participants. The factual information given in the examples was based on scientific articles, website information, and information from the interviews, and was checked for accuracy by an expert in the field. The medical examples were about gene identification, pre-implantation diagnostics and affordable drugs. The food examples dealt with broccoli and lung cancer, an allergy-free apple, and a DNA-based slimming pill. The factual information was given on sheets, while the moderator read an accompanying text that clarified the information (see Appendix 4). This should make the information the participants in the different focus groups received the same as much as possible.

One of the examples, the one on gene identification, was adapted for the two patient groups. The rheumatism patients discussed the use of so-called 'biologicals' as an example of medicines that were especially designed with the help of gene identification, and the celiac disease patients received an explanation about how gene identification might contribute to a better diagnosis of celiac disease and improved treatment methods. The three other groups considered the example of gene identification more in general, without further specification related to their backgrounds.

In the second part of the focus group discussions participants discussed several themes regarding the communication about gene research in more general and abstract terms. First, participants discussed their own roles and influence on gene research, followed by their need for information and knowledge, and the importance of knowledge and information about gene research in general. Thereupon, participants talked about other actors' opinions about and roles in gene research and how communication practices on gene research are taking place. Finally, they discussed the role of trust in this process.

In the following sections, the results of the study will be presented. Participants' perceptions of science communication strategies regarding gene research are outlined in order to describe the key views of inexperienced public participants, active consumers, patients, and experts. Quotes from participants are included to exemplify the results. These are always the verbatim texts. Translations were done by one of the researchers.

**Table 5.2: Overview of the discussed examples in the eight focus groups**

| | *Inexperienced public* | | | *Consumers* | *Patients* | | *Experts* | | |
|---|---|---|---|---|---|---|---|---|---|
| **Group** | **1** | **2** | **3** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** | **Total #** |
| *Medical examples* | | | | | | | | | |
| Gene identification | V | V | | | V | V | V | | 5 |
| Pre Implantation Diagnostics | V | V | | | V | V | V | | 5 |
| Affordable drugs | V | | | | V | | V | | 3 |
| *Food examples* | | | | | | | | | |
| Broccoli and lung cancer | | | V | V | | | | V | 3 |
| Allergy-free apple | | V | V | V | | V | | V | 5 |
| DNA-based slimming pill | | | V | V | | | | V | 3 |

## 5.3 Results from the focus group discussions

In this section, first, some general observations and information will be presented (5.3.1). Then, the participants' associations with and perceptions of gene research are described (5.3.2). This analysis provides both contextual information about the groups and information about the attitudes of the different publics in general. Next, the attention turns towards the main goal of the study and participants' opinions about the main themes, communication about gene research (5.3.3) and trust and power (5.3.4). Finally, the main findings will be summarized and discussed (5.3.5).

### *5.3.1 General observations*

In Table 5.3 an overview of the number of quotations per theme is given, for each group as well as in total. This overview is not meant to give an exact answer to the question how much time was spent on themes, since, although the number of quotations can be given, the length of the quotations did differ from group to group and from participant to participant. When reading the table, it has to be kept in mind that often several codes were given for one and the same quotation, since a participant could address several themes within a single sentence or within single turn in the discussion.

In total, among all participants, 2737 quotations have been recorded from the discussions. When those from the moderators were included, 3762 quotations have been spoken out. What is striking (in the first rows of the table) is that the total number of quotations per participant in both expert groups (234 for medical experts and 276 for food experts) was significantly smaller than that for members of the other groups. This means that experts spoke longer when contributing to the discussion, since the total amount of time per discussion was the same for all groups (approximately two hours). The data also showed that the moderator interrupted less frequently in the medical experts group (The difference between the total number of quotations and the quotations attributable to the participants themselves is 65 for medical experts).

An examination of the attention devoted to each theme demonstrates that both rheumatism patients and medical experts paid less attention to associations with gene research than did the other groups (rheumatism patients: 18 quotations; medical experts: 20 associations). Since the rheumatism patients were the first group that took part in the discussions, they were not specifically asked about their associations. After their spontaneous associations it was decided to adapt the protocol and participants were asked for their associations about gene research first. Medical experts paid less attention to this issue (20), also because they had fewer turns in total. Furthermore, the table shows that in the third inexperienced public group less attention was paid to the theme of communication (11), while both expert groups (medical experts: 41; food experts: 46) regarded this an important issue as they paid relatively more attention to this theme. The third inexperienced public group paid less attention to the theme of knowledge than did the other groups (16). With regard to the sources mentioned, the first inexperienced public group also paid much attention to sources (52), while both the active consumers (3) and the medical experts (0) paid no or hardly any attention to this sub-theme. Medical experts paid much attention to the role of actors in gene research. Finally, rheumatism patients hardly discussed the theme of trust (4), due to the fact that, inadvertently, this group had not been asked about this issue. Therefore, the quotations made represent spontaneous statements. Not all sub-themes were discussed to the same extent within the different groups, but these differences were not very marked. Since the main goal of this exploratory study was to describe the range of sub-themes and related issues or arguments the observed differences in number of quotations did not affect the validity of the data (cf. Kidd & Parshall, 2000).

**Table 5.3: Overview of number of quotations[a] per theme[b] per discussion group[c]**

| | *Inexperienced public* | | | *Consumers* | *Patients* | | *Experts* | | |
|---|---|---|---|---|---|---|---|---|---|
| **Group** | **1** | **2** | **3** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** | **Total** |
| Number of participants | 10 | 9 | 9 | 7 | 10 | 10 | 9 | 6 | 70 |
| *Amount of attention spent (in number of quotations per group)* | | | | | | | | | |
| Participants | 417 | 311 | 390 | 316 | 302 | 491 | 234 | 276 | 2737 |
| Other[d] | 176 | 127 | 114 | 118 | 128 | 179 | 65 | 118 | 1025 |
| Total[e] | 593 | 438 | 504 | 434 | 430 | 670 | 299 | 394 | 3762 |
| *Gene research associations and examples* | | | | | | | | | |
| Association | 56 | 63 | 72 | 40 | 18 | 34 | 20 | 58 | 361 |
| Medical examples | 237 | 89 | - | - | 166 | 119 | 72 | - | 683 |
| Food examples | - | 62 | 185 | 160 | - | 89 | - | 102 | 598 |
| *Communication* | | | | | | | | | |
| Communication | 26 | 26 | 11 | 31 | 29 | 31 | 41 | 46 | 241 |
| Knowledge | 32 | 23 | 16 | 33 | 26 | 43 | 24 | 17 | 214 |
| Sources | 52 | 15 | 23 | 3 | 18 | 30 | 0 | 15 | 156 |
| *Trust and power* | | | | | | | | | |
| Influence | 64 | 50 | 51 | 33 | 37 | 41 | 38 | 45 | 361 |
| Role | 70 | 60 | 61 | 47 | 42 | 65 | 82 | 57 | 484 |
| Trust | 30 | 26 | 12 | 17 | 4 | 42 | 20 | 16 | 167 |

[a] One quotation consists of the words uttered from the time one participant began speaking until another participant started.
[b] More codes per quotation are possible. [c] Each discussion lasted approximately two hours. [d] These are statements made by the moderators and statements that could not be ascribed to one particular participant. [e] Number of quotations of participants and moderators together.

Another general observation that emerged from the focus group analysis was that, in a general sense, all four types of focus group participants reacted in a similar way to the themes. For example, the participants' own frame of reference was often the point of departure for their answers. A subtle distinction is that this could be observed for participants from all groups, but it was most easily recognizable for participants from the patient groups. Inexperienced public participants sometimes drifted away from the central issue, but so did experts. It has to be kept in mind that in some cases participants did not that clearly discuss certain sub-themes or issues, although through repeated coding, the research team tried to avoid not being able to code issues.

### 5.3.2 *Opinions on gene research*

In this section, the participants' opinions on gene research are discussed with the aim of providing contextual information for the main part of the analysis. First, the associations group participants made with gene research will be outlined, and then their perceptions of the medical examples will be discussed, followed by perceptions of the food examples. The accompanying text of each example read during the sessions is available in Appendix 4.

*Associations with gene research* - Associations with gene research could be made spontaneously during the discussion. At the start of the session, participants were also asked which associations they had with gene research. A broad spectrum of associations was reviewed. Associations were related to 'white' (industrial), 'red' (medical) or 'green' (agricultural) genomics, and varied from positive to negative connotations. Many associations were mentioned only once, or only a few times, while some were addressed by all groups. The most frequently mentioned associations dealt with the complexity of gene research (referred to 50 times), and the economical interests that play a role in gene research (32). Furthermore, ethical issues were mentioned frequently (26), as was the fear that the wrong kind of people might influence gene research (18). Other associations that were brought up more frequently than other associations were cloning (16), risks (16), genetic manipulation (15), the relation to inheritance (15), agriculture (14), the fear of manipulation (12), the concern about long-term effects (12), chain reactions that are difficult to stop (11), and the need for critical attention (11). A closer look at the associations per group showed that the inexperienced public participants in the first group talked longer about the effect of economical interests. In the third group, the possibility of cloning and the fear that the 'wrong' people might become involved and perhaps may even manipulate results was debated. Active consumers mostly referred to the complexity of the issue, the role of economical interests and the question of responsibility. Patients especially referred to the complexity of gene research, while experts raised the issue of the relationship with agriculture, the risks of gene research, and the results of the Eurobarometer studies, or other findings that showed that people's behaviour is different than said beforehand.

*Perceptions of the medical examples* – The medical examples – dealing with gene identification, pre-implantation diagnostics (PID) and affordable drugs – were discussed by inexperienced public participants, by patients from both groups, and by the medical experts. Regarding *gene identification*, at first inexperienced public participants reacted positively about the possibility for improving diagnostics and personalized medicines with the help of gene identification. At the same time, in both groups more ambivalence was manifested when questions were asked about privacy aspects when analyzing DNA, about what the costs and benefits would be and for whom, about the capability of science to actually achieve this goal since other factors are involved as well, and about the risks involved. Both rheumatism patients and celiac disease patients saw advantages in the possible use of gene identification, but they also referred to issues such as privacy concerns when analyzing DNA, ethical aspects and the role of insurance companies. Medical experts mainly pointed to the complexity of personalized medicine, but agreed that diagnostics could be improved this way.

Both inexperienced public participants and patients held the opinion that decisions regarding *pre-implantation diagnostics* (PID) are personally embedded, i.e., one can only make a deliberated decision when one is personally involved. Participants in all groups mentioned the same types of arguments when discussing this example. PID might provide benefits but it is a slippery slope and the question is how far these technologies should be allowed to proceed. Ethical and religious arguments ('designer babies', 'playing God') were brought up, besides arguments of economic nature (will the technology be available for everyone?) and the psychological stress that a treatment may give. Experts added that in practice most people do not pursue this kind of screening, but it shows what science is capable of. They stated that information and deliberation were needed to help people learn how to handle this dilemma.

The development of drugs, with the help of gene research, that is very expensive (*affordable drugs*) prompted inexperienced public participants and patients to respond that in the future these medicines will become cheaper for consumers since production and development costs will go down. According to the participants, if the medicines help, the costs are not that important; the risks deemed more important. Also important is information about the criteria for treatment, to prevent a social divide due to people being excluded based on their age or other factors. Experts thought that the costs had to be seen in relation with the costs of other products and they emphasized that which costs are acceptable is more a decision for society as a whole.

*Perceptions of food examples* – The food examples were about broccoli and the chance of lung cancer, about an allergy-free apple, and about a slimming pill based on analysis of a person's DNA. They were discussed by inexperienced public participants, active consumers, celiac disease patients (only the example of the allergy-free apple), and food experts. The inexperienced public participants found the example, *broccoli and cancer*, in which eating broccoli three times a week was recommended in order to prevent lung cancer when a person carries certain genes interesting. But they thought that this recommendation would not cause people to change eating habits, as the effect was believed to be too small, and other factors would interfere with these effects. The moral question was brought up whether people would be happier if they knew that they carried certain 'risky' genes. Participants thought that the ways people react to this kind of information is highly variable. Active consumers thought that these types of diets are too much of a challenge. Something similar already exists in practice, but it is not a very sophisticated diet. Furthermore, the recommendation runs ahead of the troops since the genes in an individual do not have to express themselves. Participants believed a general and free to choose recommendation for a healthy diet a better alternative. Food experts wondered how well the study on which these recommendations were based was performed since not that much is known yet. Are all contributing factors under control? Besides, it is known that knowledge does not necessarily imply that people act accordingly, and trying to stick to such a diet would be impractical.

The development of an *allergy-free apple*, i.e., an apple that people would not be allergic to, would be a positive one, according to the inexperienced public participants. Some participants said that they would be willing to buy and eat these apples if they were allergic to regular apples. However, they stressed that there has to be a choice in products. Although participants responded positively, they would like to see that a long-term effects and risks be studied. Other participants drew the attention to the cost-benefit calculation of such a product and wondered whether enough people would need or buy such apples. Active consumers saw no difference between apples selected and developed in this way or those selected in a natural way, but did not want public money spent on the development. Some participants stated that enough alternative options for fruit are available. Celiac disease patients considered this way of selecting as equal to natural selection, but they were also concerned for negative long-term effects. Food experts emphasized that the gene technique would be a quicker solution for the growing group of people that is allergic to apples. They also mentioned that it would offer a real benefit for the consumer. And, one of the food experts stressed his deeper scientific interest in the cause of allergic reactions.

Regarding the example of the *DNA slimming pill* participants' responses showed a consistent pattern in all groups. Inexperienced public participants' first reaction was that the offering of a slimming pill based on the analysis of a persons' DNA was a fraud as the only way to lose weight is by exercising and by restoring the balance of one's metabolism. If it would work at all, it would be fantastic for really sick people, but, at the same time, participants uttered their fear of potential abuse, i.e., people taking the pill while still maintaining wrong eating habits. Some participants were willing to pay for a working DNA slimming pill. Active consumers stressed the urgency to change both eating habits and one's exercising habits; it should not bring the metabolism further out of balance. They doubted of the makability of the world and wondered where the responsibility for behaviour lies. Finally, food experts emphasized eating habits, but they also pointed out that the combination of eating and exercising habits should be further investigated. Additionally, they stressed the fact that, in today's society, consumption receives too much attention, and they pointed at possible negative effects for sustainability.

All in all, in the discussions of both the medical and the food examples, in all groups most of the time the pros and cons were weighted against each other, which resulted in a nuanced debate. Negative attitudes were expressed, but so were positive ones. Differences were observable among the groups, but, at a basic level, similar opinions were expressed.

### *5.3.3 Communication about gene research*

All groups discussed the theme of communication about gene research. Within the larger theme, by means of grouping and rearranging the issues, the analysis revealed several sub-themes. These were: (a) *interest in gene research*; (b) *biased information and how to control for this*; (c) *the need for information and knowledge*; (d) t*he nature and the quality of sources of information*; (e) *passive and active elements in the communication process* (see Table 5.4 for an overview).

*Interest in gene research*

In all groups, participants linked interest in an issue such as gene research to their personal interest or involvement in the issue. Some inexperienced public participants showed a general interest in gene research, while others admitted that they were not very interested. Inexperienced public participants stated that interests were not only related to general interests or personal interests, but also to professional interests, i.e., interests are role-dependent. As reasons for their (limited interests), participants mentioned the available time (since there is too much to know) and the quantity of information available (information overload). On the one hand, general interest in gene research did not always imply that participants actively searched for information. They thought that news coverage was sufficient. On the other hand, personal interests led to active searching behaviour. In the following, the findings will be illustrated by quotes from participants.

> 'Interest in gene research issues is important. But it is…, it is too much to know about. If one would work in the health sector, then, of course, it would be of more interest. But if one works in the technical sector, as I do. Yes, I will not go deeply into that subject when there's a book available on genetics and one on mechanical engineering, I will choose the book on mechanical engineering' (Inexperienced public, male).
>
> 'Yes, one wants to know when it affects one personally' (Inexperienced public, female).
>
> 'To gain more in-depth knowledge is hardly worth it, when you don't work in the field' (Inexperienced public, female).
>
> 'I don't actively search for information. But I am told, regularly, things. But I will not go deeply into it. When something is in the news papers, I consciously read it' (Inexperienced public, female).

Just as inexperienced public participants did, active consumers distinguished between personal and general interests as reasons for being interested in gene research. A different focus was found for the following issues. According to the active consumers, the general public has little interest in the issue. They emphasized that dissemination of information is useless unless people show interest. And they stressed the need for research in order to find out how to raise such interest.

Patient participants from both patient groups identified personal involvement as the key to interest in gene research. They agreed with the active consumers that the general public has little interest, but attempts to create such interest would be futile. They indicated that there is too much to know about all issues. However, they also argued that without information dissemination, public interest would even diminish. Communication means such as the news media, and public lectures by doctors were mentioned as ways to raise interest in and awareness of these issues.

> 'I find these [lectures] interesting. The information will be explained in other ways than the doctor does: since he just mentions a few results and then you think, what is this all about, while in a lecture it is more clearly explained. And asking questions is part of it. I think that can help people very well' (Celiac disease patient, female).

Experts also discussed interest in gene research. Medical experts related interest to personal interests and to trust in experts. A medical expert pointed out that the interests of experts do not always coincide with those of citizens and, therefore, experts need to explain more often what results of gene research imply. Furthermore, medical experts clearly distinguished people with different needs for information, and they made it clear that behaviour and interests do not always coincide. Interests are role-dependent: a patient is interested in other information than is a citizen. Food experts emphasized that interests increase when concrete products are in sight, and personal affection starts playing a role. Like the active consumers, they would like to see more research dedicated to studying how interests may be raised.

> 'For some issues I have complete confidence in people that can find the best solution for me. But, some issues attract my interest, before I take a decision regarding the issue. In those cases I want to know exactly what is going on. And if one may generalize, you will see a rich variety of people. Some people don't want information; they live perfectly without this knowledge, with a kind of *blunting experience*, while others need it to be optimally informed. Patients show the same behaviour. It has to do with their need for information' (Medical expert, male).
>
> 'Beforehand, about 80% of the people want a gene test, but when it is available most people don't use it' (Medical expert, male).
>
> 'Also to find out what determines the consumers' opinion; not to influence this opinion, to take advantage of it, but to pick up the communication; to find out what puzzles us' (Food expert, male).

*Biased information and how it can be controlled for*

Inexperienced public participants broached the sub-theme of biased information and the desire for control mechanisms that would prevent such bias. Not only did they state that scientific results are sometimes manipulated, they also said that information from industry is always biased, and, more generally, that *all* actors provide information with a certain interest. Participants mentioned several of these control mechanisms. In a democratic society, journalists could play a critical role, since most information reaches the general public through the media. Appointed ethics committees could also raise questions. Furthermore, participants mentioned other actors (e.g., non-governmental organizations) that could play a critical role. Scholarly systems, such as in use in the scientific community, are also needed for other sectors. The broader context, or knowledge, of issues should be provided to make deliberated judgments possible. Openness and transparency of information were identified as the key solution to this problem. And acknowledgement of the sources of information is a trust base for scientific research, since this would expose the interests of actors involved. A final solution that was suggested is that people themselves should actively search for information.

> 'I think, there is only partial openness. It could, perhaps, of course be my own experience' (Inexperienced public, male).
>
> 'They [scientists] sometimes have a specific focus, a complete tunnel vision. To follow that critical, and to provide opportunities to look, this, in another way, to look at it. Ethics committees, that kind of stuff, you really need those in a country like ours' (Inexperienced public, female).
>
> 'As much as possible, the broader connections should be mapped out, yes, of course. Only then, well-considered choices can be made' (Inexperienced public, male).
>
> 'Well, I think that every actor playing a role in this has a certain interest. Whether it concerns industry, the scientist, the journalist, or the political parties, they all have their interests. And these interests may contradict each other. These interests can be in line with each other. It is possible. I think that it is very important to provide openness' (Inexperienced public, female).

Active consumers discussed the sub-theme of biased information. They stated that information may be, and often is, biased. Like inexperienced public participants they advocated a system of publishing research results for actors other than research institutes. The participants stressed the availability of information and the provision of reliable information by neutral and independent organizations such as the consumer association, governmental research institutes, and schools.

> ‘Look, of course, information should be available. But, what you also stressed, what is that information? What we read in newspapers, is that information? It is obvious that that is coloured information. And it is obvious that citizens will be manipulated with it. Just look at the opinions on genetically modified food in the Netherlands and in the rest of Europe. Large differences are found between these’ (Active consumer, male).
>
> ‘No, all kinds of, but easily, but easily things are exaggerated. And there should be one single organization […] that just, back to the basis, can provide neutral information’ (Active consumer, female).
>
> ‘I think it is also a task for schools’ (Active consumer, male).

The sub-theme of biased information was discussed very briefly by patient participants. Celiac disease patients referred to their experiences with journalists and newspapers. Not only information from newspapers was considered not fully trustworthy, but also information from the Internet is framed the way the sender wants it. Finally, experts paid, some, but less attention to the sub-theme of bias; one participant stated that, at least on TV the facts are specifically framed.

*The need for information and knowledge*

In all groups, the importance of knowledge and the need for information were stressed. However, groups identified different issues in their discussions about why and how knowledge and information are playing a role in communication strategies. Inexperienced public participants mentioned some issues related to the need for information and knowledge; more time was spent on biased information, on how to prevent bias and on the sources of information. They emphasized the need for more information. It was discussed who should be in charge of providing the information. And participants talked about the difficulty for governments to provide the right information, since individuals’ levels of knowledge differ significantly. In addition, it was thought that, although information should be disseminated in accessible, popular language, more knowledgeable people would not read these popularized articles. This led to the conclusion that people should actively search for information themselves.

> ‘But for governments it is quite difficult to offer information since the level of knowledge among people varies widely. Information written in popular language will not be read by more knowledgeable people. Thus, were to start then? These people should actively search for information themselves’ (Inexperienced public, male).

Active consumers placed a different emphasis upon the need for information and knowledge. They discussed this sub-theme extensively. Dissemination of information was considered an important right in our contemporary society. They believed that decisions should be based on information and that the availability of a variety of sources would help in developing a deliberated opinion. On the one hand, the participants also found that information dissemination is a duty for those people capable of understanding the communication process. This finding is comparable to the finding that research institutes were considered to have the duty to report study results, preferably in an understandable way. On the other hand, freedom of choice was emphasized, together with open access to information. People should not be forced to collect information on an issue. Although participants indicated the need for popularized information, they also stressed that information is only part of the communication process. Communication and knowledge are two other important elements, and, according to the participants, other (related) concepts. All in all, participants regarded both information and information dissemination as complex concepts. Finally, active consumers considered some problems regarding the dissemination of information: information overload and the fact that the different meanings information may have for different actors lead to difficulties in the process of choice.

> 'You see! That the basic materials should be available, that I find an important condition in our society. You see, some societies are not ready for it [open information]. But, we are raised in the tradition of being able to choose. … So, we are raised in that tradition, weighing the pros and cons, continuously choosing' (Active consumer, female).
>
> 'Information is of course just one side. That does come from above, or from the researchers, or from something else. And communication does mean that one listens to the one who wants to know. I personally think that few ways are available to tell which kind of interests one has. Knowledge is something else. Knowledge is something one can build up from wanted and unwanted information that one gathers' (Active consumer, female).
>
> 'Then there's the story of what I just said, that information, words have different meanings in different languages. That is what is happening here. Information has a different meaning for Greenpeace than for Unilever; the same information. It is something one has, something one has to take into account. You asked if everyone needs knowledge. Yes, but immediately, or, at least, one should not accept that people do the same with it, or that they understand it the same way' (Active consumer, male).

Compared to inexperienced public participants, patients clearly reported a higher need for information. However, this information was mainly restricted to their interests: disease-related information. Both patient groups stressed the need for empowerment, but in different ways. Rheumatism patients actively searched for information related to their disease and, in the course of this process, also communicated this information to others, mainly other patients. They indicated that the information process with doctors had improved over the course of time. Celiac disease patients felt the need for empowerment more urgently, since experts (especially general practitioners) often have insufficient knowledge about the disease, and, therefore, these patients started to actively inform these experts and others about information related to their disease. More generally, patient participants found the dissemination of information in popular language important, despite the fact that they were aware that too easily such information may lose some of its essential content. Like the active consumers, they discussed the issues such as freedom of choice, and thought that forcing information onto people would not work. Knowledge was considered an essential prerequisite for taking part in a discussion. For this knowledge patients depend upon experts, since it is impossible, even for patient associations, to acquire all relevant expertise. Experts were considered the 'knowledge keepers'. According to a participant, as lay people are perfectly capable of making moral judgments, in the case of ethical issues, dependence on experts should be avoided.

> 'At the moment it is changing again. It used to be that rheumatism counsellors ... each half year they started a new group. Something was told about the significance for your life. Counselling was given for some aspects … People exchanged information, so that one did not need to find it out by oneself' (Rheumatism patient, female).
>
> 'What one notices is that it is important that people learn to know companions in misfortune. Actually, that should be the first thing to be organized. It is, well, one gets a chronic disease and you get a lot of information and your life turns upside down. It means that you need to learn to live a new life' (Rheumatism patient, female).
>
> 'I do think they [GPs] have access to information, but they don't have the time. What we have to do is feed them a little bit' (Celiac disease patient, female).
>
> 'I provided my GP with printouts about celiac disease. But I think he put them away. Some professional caretakers have never heard of this disease' (Celiac disease patient, female).
>
> 'An active attitude is stimulated by the patient association' (Celiac disease patient, female).

Participants in the expert groups brought up several issues related to the need for information and communication that had already been mentioned before in the other groups, but some new elements were also discussed. Medical experts paid most attention to the issue of knowledge and they related the discussion to 'citizens', while food experts spoke about 'consumers'. According to one medical participant some people do not have a need for knowledge, while other people have an urgent need for being informed; they cannot function without knowledge. Medical experts stated that for issues other than genomics, for example smoking or AIDS, the same pattern can be observed. Some people want to rule out risks, others do not. It leads to the reflection that the importance of having knowledge can be taken differently: as a need for knowledge or access to knowledge at the right time. Another observation is that in the process of knowledge gathering it is important who is helping the citizen (e.g., doctors), and knowledge about gene research is not limited to the technical details of gene research itself, but it also includes knowledge on related issues, such as care, for example. An overload of knowledge could potentially lead to the loss of a general, coherent view.

> 'The importance of knowledge is dualistic. As a citizen one doesn't need all the knowledge on the condition that this citizen can have access to the right information at the right time (Medical expert, male).'
>
> 'Knowledge or rather the urge to mobilize knowledge is wanted when a person has to decide about an issue. It concerns knowledge of genomics, but also more general issues as care in general (Medical, expert, male).'

Viewed at in the context of the need for knowledge, the same observation was made for doctors: some need much information, while others do not, but their decisions may vary in spite of them having available the same information. The contextualisation of knowledge was identified as an important issue. The medical experts distinguished among different kinds of knowledge. And in this context it was pointed out that citizens should be taken seriously with regard to more emotionally loaded knowledge, and that they do not need expert knowledge as long as they can trust their sources. Furthermore, citizens are able to make decisions about issues without having all relevant knowledge.

> 'In general, citizen's knowledge level is low, but, still, by way of other means, this citizen get's a *gut feeling* of the issue, and can make reasonable decisions. That's why it is useful to involve citizens in the decision-making process' (Medical expert, male).

Food experts emphasized different aspects of knowledge than medical experts did. They all agreed that having knowledge about gene research was important. The reasons mentioned were: knowledge encourages new research; it allows people to make deliberated decisions; consumers use it (besides other considerations) to base their purchasing decisions on it, and, finally, one negative response may influence the public's opinion. Information dissemination and education are means to distribute the knowledge. However, they stated that not only knowledge is playing a part in the decision-making process; the consumer's pre-existing attitudes also play a role. And it has to be kept in mind that a more knowledgeable consumer is not necessarily more accepting of gene research.

> ‘In my view it is not the case that the more the consumer knows, although this is at times underestimated, the more he will accept it. I’m convinced this is a difficult misconception’ (Food expert, female).

*The nature and the quality of sources of information*

The participants discussed several sources that provide information on gene research or on other scientific themes. Additionally, they talked about the quality of the sources. Inexperienced public participants mentioned radio, television, newspapers (quality newspapers and other newspapers), the Internet (especially for providing additional information), medical research studies or medical journals, professional journals, and information from government sources (e.g., Postbus 51 – a series of media campaigns on issues of general interest run by the government). Regarding the sources and the quality of the information disseminated, the participants made the following observations. According to a participant, governments should not play a role in informing people about gene research. Another participant claimed that the government was rather silent. Some more comments were given on the degree of detail of the information. Television programmes were considered to be too superficial, or they were believed to be inadequate with respect to the degree of detail of the disseminated information. This same criticism was expressed with regard to the newspapers. For some participants, newspapers were the primary source of information, and more in-depth information would be appreciated. Participants stated that articles appeared in newspapers based on newsworthiness criteria rather than on how useful the information is for the readers. According to them, sometimes it happens the other way around; developments in society influence what the media pay attention to. More in general it was argued that the amount of attention devoted to different subjects is related to the economic interests of the various parties involved. In part, openness of information has to do with information that actors want to be accessible. Other sources, such as the Internet, offer the possibility to compare information, and therefore, have become important sources of information.

In their discussions on information, active consumers observed more general aspects of information sources. Stakeholders should provide open access to information. According to these participants, since all information is biased in some way or another, a solution would be to put independent organizations in charge of that task. The education sector should be a source of disseminating information on gene research as well.

Patient participants indicated that they relied on information sources from their patient associations, beside the information distributed by the general media. They also mentioned that these media sources do not always give reliable information, as they let their own interests prevail. However, the two patient groups differed in the way they saw their doctors. Rheumatism patients considered doctors reliable sources of information, due to a relationship built up over many years. Celiac disease participants, on the contrary, regarded their doctors as some of the least reliable sources of information, which is a direct result of the frequent information deficiency of their GPs with regard to celiac disease.

> 'Every two weeks I get an injection from my GP. I visit the rheumatologist every two months. I must admit that, with much clarity, with much time available, I think that, in good collaboration, decisions can be made' (Rheumatism patient, male).
>
> 'My negative experience: … In the first place, he is not interested in your story. … Secondly, I discovered he didn't know about the myosin-IXB-gene on the 19th chromosome. … He tried to cover it up, he pretended to know, but he didn't …' (Celiac disease patient, male).

With respect to the different kinds of information sources and their quality, experts discussed the reliability of information due to framing. Several kinds of information sources were mentioned, as well as educational information.

*Passive and active elements in the communication process*

Communication and information are closely related in the communication process. Inexperienced public participants talked more about information than about communication. The need for transparency and openness in the communication process was an issue the participants reflected on. According to inexperienced public participants transparency exists only partially, and actors such as journalists or ethics committees could play a role in improving transparency. They also pointed out that biased information might endanger the information process. Finally, participants mentioned with whom they communicate about gene research, with family and friends and at work.

> 'Yes, I think that, in the end, it is a political consideration. This country is a democratic country. There are control mechanisms, transparency. I think that openness is important' (Inexperienced public, male).

Active consumers pointed out that for them communication is a powerful tool. This communication process is complex and could be improved: by listening to the public's needs and interests; receivers may give input and communicate their interests as well. Communication means listening: information is dissemination, and knowledge is something one can build up from wanted and unwanted information.

Patients considered communication and information important themes. At least informing the people was thought to be important, complemented by discussion. Openness and transparency were regarded as important aspects of a communication process, but sometimes economic interests appeared to be more influential, and taking the pulse of the party is forgotten. Another observation was that communication is a complex, time-consuming process, in which the ability to influence is sometimes more important than the communication itself. Two final observations dealt with the communication process. The participants pointed out that, when knowledge is not communicated, individuals have to communicate their own wishes and empower themselves, and, the question is who is interested in the communication.

> 'If people want to listen is something else, but to provide information is essential. That is also why I personally would actively inform other people that are interested. Having decision-making power is another issue. To inform audiences is the way to start; other activities will follow' (Rheumatism patient, female).

Experts too, focused on transparency and open communication. Medical experts argued that different ways of communication were needed in the changing context of genomics, possibly involving different relations with the public. They paid more attention to education and the dissemination of information than to public participation, although one expert reported some interesting experiences with participation activities. His conclusion was that, although the public's knowledge levels are low, involving citizens in the decision-making processes is a good thing, since citizens are able to make informed decisions. Finally, medical experts commented that scientists need to learn how to properly communicate with the public. A food expert brought up the need for communication, stating that the agricultural sector had decided to get involved in the development of the policy changes they deemed necessary. With this new policy in place, communication became an important issue. Participants argued that, rather than merely passing on information, researchers should engage in a real, two-way communication process. According to the participants, other key elements of this communication should involve transparency, diversification of the ways in which information is delivered, taking emotional arguments into account by decision makers, and engagement in communication processes is a task for all actors involved. More so than did food experts, medical experts emphasized education and the dissemination of information as important prerequisites for the communication about gene research.

> 'We have been doing poorly. Nowadays, more attention is being paid to communication, such as talking with organizations outside the scientific community, with the ordinary consumers' (Medical expert, male).

‘Communication doesn’t mean PR, but rather, informing people, for example at Rotary clubs and country women’s associations’ (Medical expert, male).

**Table 5.4: Overview of the sub-themes and issues of communication on gene research**

| | General public | Consumers | Patients | | Experts | |
|---|---|---|---|---|---|---|
| | **Inexperienced public** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** |
| *Sub-themes and issues* | | | | | | |
| **Interest in gene research** | | | | | | |
| Involvement | V | V | V | V | V | V |
| No interest | V | | V | V | V | |
| Related to personal involvement/ experiences | V | V | V | V | V | V |
| Related to professional involvement | V | | | | V | V |
| Related to inexperienced interest | V | V | | V | | |
| Too much to know/ focus restricted to interesting subjects | V | V | V | V | | |
| Interest leads to more knowledge | V | | | | | |
| Interest does not equate to (active searching) behaviour | V | | | | V | |
| More interest leads to more active searching behaviour | V | | | V | | |
| The general public is not interested | | V | V | | | |
| High interest of the public | | | V | | | |
| Related to trust in actors | | | | | V | |
| Study interest | | V | | | | V |
| Need for information | | V | | | V | |
| Role-dependent | V | | | | V | |
| Interest should not be obligatory | V | | V | | | |
| Power plays a role in interest | V | | V | | | |
| **Biased information and how it can be controlled for** | | | | | | |
| Biased / tunnel vision | V | V | | V | V | |
| Overload | V | V | V | V | V | |
| Manipulation of results | V | | | | | |
| Control mechanisms | V | V | | | | |
| Role of journalists | V | V | | | | |
| Role of ethics committees | V | | V | | | |
| Role of government – task in informing | V | V | | | | |
| Need to provide wider context | V | V | | | V | V |
| Interrelatedness of issues | V | | V | | V | V |
| (Dis)trust in sources | V | V | V | V | V | |
| Selective openness | V | V | | | | |
| Active searching behaviour | V | | V | V | | |

**(Table continues)**

**Table 5.4 (continued): Overview of the sub-themes and issues of communication on gene research**

| | General public | Consumers | Patients | | Experts | |
|---|---|---|---|---|---|---|
| | **Inexperienced public** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** |
| *Sub-themes and issues* | | | | | | |
| **The need for information and knowledge** | | | | | | |
| Need for information | V | | V | V | V | V |
| In lay language (popularize) | V | V | V | V | | |
| Importance of knowledge | V | V | V | V | V | V |
| Kinds of knowledge | | | | | V | V |
| Interpretation of knowledge is context-dependent | | V | | | V | V |
| Duty to inform | V | V | V | | | |
| Active attitude | | V | V | V | V | |
| Possible to 'mobilize' knowledge | | V | V | V | V | |
| Role of economic interests | V | | | | | |
| Open access to information | V | V | | | V | |
| Lay-expert different meaning | | V | V | | V | V |
| Deliberated decision/ opinion | V | V | V | | | V |
| As education | | | | | V | V |
| Information dissemination | V | V | V | | V | V |
| More knowledge but not more acceptance | | | | | | V |
| Risks | | | V | | V | |
| Freedom of choice | V | V | V | | | |
| Knowledge as an element in the design of the communication process | | V | | | V | |
| Involvement of citizens | | V | | | | |
| Too much knowledge leads to confusion | | | V | | V | |
| Improving the information process | | | V | | | |
| Capability to judge information | V | | | | | |
| Sources of information | V | | | | | |
| **The nature and the quality of sources of information** | | | | | | |
| Media (TV, radio, Internet, newspapers, magazines) | V | V | V | V | V | V |
| Libraries | | V | | | | |
| Journalists | V | V | V | V | V | V |
| Politicians | | | | | | V |
| Research institutions | | | | | | V |
| Industry (leaflets) | | | | V | | V |
| Experts | | | | | | V |
| Doctors (lectures/ consults) | V | | V | V | V | |
| Government (participation/ information brochures) | | | | | | V |
| NGOs | V | V | V | V | V | V |
| Consumer associations | V | | V | V | V | V |
| Patient associations | | | V | V | V | |
| Farmers | | | | | | V |
| Educational institutions | | V | | | V | |
| No role for governments | V | | | | | |
| Depth of information | V | | | | | |
| Newsworthiness criteria | V | | | | | |
| Open access | V | V | | | | |
| Attention if economical interests | V | | | | V | |
| Comparison of sources | V | | | | | |
| Framing of information | | | V | | V | |
| Reliability of doctors | | | V | V | | |

**(Table continues)**

**Table 5.4 (continued): Overview of the sub-themes and issues of communication on gene research**

| | General public | Consumers | Patients | | Experts | |
|---|---|---|---|---|---|---|
| | **Inexperienced public** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** |
| *Sub-themes and issues* | | | | | | |
| **Passive and active elements in the communication process** | | | | | | |
| Complex process/ information complex | V | V | V | | | V |
| Need for transparency and openness of communication | V | | V | V | V | V |
| Distrust / trust in actors (such as journalists/ ethics committees) | V | V | | | V | |
| Broader context | V | | | | | |
| Tunnel vision / biased information endangers information process | V | | | | | |
| Discussing information in other social situations | V | | | | | |
| Hardly any communication available | V | | | | | |
| Two-way communication | | V | V | V | V | V |
| One-way communication | | V | V | | V | V |
| Decision-making power | | V | V | | V | V |
| Participation of the public | | | V | | V | V |
| Informed choice | V | | V | | | V |
| Educational element | | | | | V | V |
| Information dissemination | V | V | V | | V | |
| Role for emotions | | | | | | V |
| Power imbalance | | V | | | | V |
| Changing context | | | | | V | |
| Importance | | V | V | | V | V |
| Need for time | | | V | | V | |
| Empowered communication | | | V | | | |
| Listening to needs and interests | | V | | | | |
| Duty to communicate | | V | | | | |
| Role of ethical aspects | V | | V | | | |

### 5.3.4 *Trust and power*

In this section, issues the participants brought up with respect to trust and power are summarized, and findings from the inexperienced public groups will be compared with findings from the other focus groups. The analysis revealed several sub-themes within the theme of *trust*, namely: (a) *(dis)trust in actors* and (b) *elements of general trust*. Subsequently, the findings related to the concept of power are presented. Sub-themes observed were: (c) *the role and influence of participants and other actors on gene research* and (d) *aspects of decision making* (see Table 5.5).

*(Dis)trust in actors*

Inexperienced public participants brought up several aspects of trust in actors and of trust in general. Actors, such as journalists, politicians, industrial actors, doctors, and even researchers, are not unconditionally trusted, due to reasons such as human fallibility and (economic) interests of the stakeholders, which may, for example, lead to the manipulation of research results.

> ‘If you read an article, and you believe its content, then, there is always the opportunity to verify it on the Internet. I am convinced that that should happen more often. Because, what he is pointing at, commercial interests are everywhere. … And a journalist who writes an article about a certain medicine will first visit the factory, and he will. What happens in the factory, we don’t know. He might be pampered; he might speak to the assistant director, who knows. That influence, he still is a human being and they are sensitive to these things’ (Inexperienced public, male).

The responses of the inexperienced public participants differed from those of active consumers. Active consumers mentioned a decline in the level of trust in government and experts among the general public, leading to large differences among actors in the degree of trust they receive.

> ‘In my opinion, during the past ten to fifteen years, so many changes have taken place in society that, I would say, that the general level of trust in government or in expertise is contested. In fact, due to this process, a general feeling of scepticism has developed, and nothing is taken for granted anymore’ (Active consumer, male).

Compared to participants from the other focus groups, patients put the most emphasis on the importance of trust in specific actors, namely doctors. According to the patients, this relationship is very important, but most striking is the way celiac disease patients distrust doctors. This distrust has to do with the doctors’ knowledge deficit regarding the disease. Other specific actors, such as researchers, *are* trusted since they control each other (through the peer review process), but more generally, there are always some people that are not trustworthy.

> ‘Yes, but now it concerns trustworthiness. Seventy, or, who knows, eighty or maybe ninety, percent of the people is reliable. But there are always some people that try to better themselves. That happens also in medical research, and in environmental organizations. As I said, they are generally fairly reliable, but at a certain moment they will have, sometimes, a hidden agenda, yes’ (Celiac disease patient, female).

The responses of the experts differed from those of the inexperienced public participants in the sense that they emphasized the complexities of a theme such as trust, while inexperienced public participants pointed out the difficulties surrounding trust. Experts emphasized that more influence is desirable in cases where actors are less trusted. Only experts mentioned the connection with risk perception, i.e., the way people deal with chance. Furthermore, long-term relationships between consumers and producers were considered important. One interesting finding was that, contrary to what was the case for the food experts, medical experts felt that their personal trust in industry had diminished. At the same time, these experts showed responses similar to those of the inexperienced public participants with respect to the declining level of trust in actors, such as industry, doctors, and political actors.

> 'I think I can join in. I became less naïve. I have been working in industry for more than thirty years, and my distrust in industry increased instead of diminished. And I would like to make some differentiations. In my opinion, the economic interests are that high on the agenda that they endanger other principles, as the number one issue of sustainability' (Medical expert, male).

*Elements of general trust*

With regard to trust in general, a critical attitude is reflected in the claim by inexperienced public participants that one should not accept information uncritically. However, these participants also indicated that a trusting attitude is sometimes the only option available. When asked which factors contribute to the trustworthiness of information, they mentioned the following conditions: the opportunity to compare different sources of information, independence of the actors that provide the information, transparency and openness of the communication process (which, for example, make it possible to verify research results), the opportunity to influence the decision-making process, scientific research into the long-term effects of new technologies, and insight in the interests of actors.

> 'One has to compare and keep track' (Inexperienced public, male).
>
> 'And believe in it' (Inexperienced public, male).
>
> 'Through control, there is no control. What he just said, one can think about politics whatever one wants; it is manipulative and so on, but it happens. There is some control, some control is taking place. That is why, in fact, on this research, on gene research, checks should take place. My sense is that these checks, at this moment, are missing' (Inexperienced public, male).

More so than inexperienced public participants, in their discussions, active consumers focused on general aspects of trust. According to them, trust is an important element in the communication process between actors, and trust is strongly connected to displayed solidarity between actors, which is currently lacking.

> 'When we talk about trust, it doesn't concern the truth. In some organizations it concerns the truth as well. But, it concerns solidarity' (Active consumer, male).

Issues related to general trust – or distrust – that (celiac disease) patient participants mentioned were similar to the responses of inexperienced public participants: long-term effects are not known, and mechanisms for assessing the reliability of research are important. However, different explanations were given by patients[3], compared to those provided by inexperienced public participants: such an evaluative role may be played by consumers' organizations, environmental organizations, and ethics committees. Finally, trustworthiness of actors is mentioned as an issue.

> 'They [consumer associations or environmental organizations] mainly warn for the fact that long-term results are unknown. Look, take the case of the DES-daughters. At that time they thought to have found a solution and only many years later it appeared to be a disaster. With genetically modified soy, who might discover in two or three generations that it causes a disaster, who knows? And at this very moment, nothing is clear about that' (Celiac disease patient, male).

**Table 5.5: Overview of sub-themes and issues with respect to trust**

| | General public | Consumers | Patients | | Experts | |
|---|---|---|---|---|---|---|
| | **Inexperienced public** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** |
| *Sub-themes and issues* | | | | | | |
| **(Dis)Trust in actors** | | | | | | |
| Journalists | V | | | V | | |
| Politicians | V | | | | | V |
| Research | V | | | V | V | V |
| Business | V | | | V | V | V |
| Experts | V | V | | V | | |
| Doctors | V | | V | V | V | |
| Government | | V | | | | V |
| Self | | | V | | | |
| NGOs | | | | V | | V |
| **Elements of general trust** | | | | | | |
| Transparent and open communication | V | | | V | | V |
| Believing | V | V | | | | |
| Long-term effects | V | | | V | | V |
| Verifiable research | V | | | V | | |
| Dominance of economic interests | V | | | V | V | |
| Listening to both sides | V | | | | | |
| Known interests/ unselfish interests | V | V | | | V | |
| Acknowledgement | V | | | | | |
| Reliable sources | V | | | V | V | |
| General decline in trust | | V | | V | V | V |
| Solidarity | | V | | | | |
| Communication | | V | V | V | | V |
| Needing information | | V | | | | V |
| Representative | | V | | V | | |
| Engagement | V | | | V | | V |

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[3] Accidentally, rheumatism patients have not been asked about trust. Their only references to trust were made spontaneously.

Experts also reported the need to restore trust and they suggested ways to effectuate this, such as by building in control mechanisms, by ensuring open and transparent communication processes, in which positive as well as negative arguments are presented, by taken the concerns of consumers seriously, and by involving consumers or citizens in the decision-making process.

> ‘To gain real trust from an actor, that is, if you take the consumer, if you take the consumers’ interest seriously, that is, the consumer is involved in the issue. If one is able to sense that that happens, to give them the feeling that it is important, then, I come to the government as an actor. In the end, it is something between the consumer and the government. When consumers don’t want the food and the government encourages it – especially, the Dutch government is promoting it the most strongly in Europe – that contributes to the famous gap between politics and citizens’ (Food expert, female).
>
> ‘Eventually, we will have to make clear what we are doing. That is, one has to communicate with the different stakeholders. … With them [opinion leaders] we have to communicate. To make clear, to provide insight into, what we do, and why we do it. And, yes, in that way we have to decide the argument’ (Food expert, male).

*Participants’ and other actors’ role in and the influence on gene research*

The focus groups approached the sub-theme of the role and influence of participants and other actors in relation to gene research from their own perspective: in their roles as inexperienced public, as active consumers, as patients, and as experts. All groups first talked about their own role and influence on gene research, and consequently, discussed the role and influence of other actors.

Inexperienced public participants in all three groups underlined the impossibility as an individual citizen to have influence on gene research. Some participants in the first group believed that some influence was possible through other channels or actors, for example, via elections, membership in political parties, or involvement in religious organizations. But it was also thought that hardly any influence was possible on governments, for example. One participant argued that, normally, influence on the political process was possible, but for him the only way to have some influence was through pressure groups. Furthermore, participants stressed that influence is only possible at the personal level, e.g., by choosing to cooperate in medical research, or by deciding whether of not to buy certain products.

> ‘I think, not much [influence is possible]. It [results of research] is being served up. It is there. And then we have to make decisions about it. But first it is being

> developed. They are, they always run ahead. And then it is being tested and there is hardly any way back, in my opinion' (Inexperienced public, male).

Other participants expressed the desire to have some influence and would like to be consulted once products have been developed. On the other hand, participants indicated that they did not want to exert influence themselves. Participant did not want to restrain developments, since they were of the opinion that research cannot be stopped.

> 'You are being confronted with it. We are not being consulted' (Inexperienced public, male).
>
> 'In earlier times, in some cases a broad societal debate was organized, but in most cases results from those debates are not taken into account too' (Inexperienced public, female).
>
> 'That is what I point at. In that sense we don't have much influence' (Inexperienced public, female).

Participants in all three groups emphasized that industry is the most influential actor in the decision-making process surrounding gene research. Various other actors were mentioned in the different groups: government, the health care sector, universities, the field of education, pressure groups, patient associations, scientists, politicians, environmental groups, ethicists, doctors (general practitioners as well as specialists), and journalists. According to them, politicians design laws, and journalists influence the political agenda, which is the reason why they might be the most influencing actor. Participants in one of the groups stated that governments not always have the proper knowledge. They emphasized that pressure groups and environmental groups can force media attention to gene research and delay research progress for a while, but they are not always fair towards the public either. Patient groups finance research but could they would have more influence if their membership were larger. Participants also stated that researchers sometimes exaggerate their findings in order to draw more media attention. This statement led to the observation that research should remain verifiable. One participant identified verifiability as the most pressing issue, and as the key to industrial and economical influence. Finally, it was remarked that the influence of industry has been too overpowering as scientific research depends too heavily on industry.

> 'In my view, that [the industry] is the most influential actor, […] because, […] those are the people that often finance [the research]. We say it is the government, but the stakeholders, the companies and the potato industry. […] In my view, they have an interest in that. That they contribute to it' (Inexperienced public, male).
>
> 'In my opinion, the equilibrium is off balance, yes. The past ten years the dependence of scientific research on industry, on the producers, has grown, while, in the

> past, scientific research was still independently funded' (Inexperienced public, male).

Active consumers, being active members of the largest Dutch consumer association, showed more optimism about their own influence than the inexperienced public participants. All participants agreed that some influence was possible, not as an individual member, but through their consumer association. The consumer association does indeed have some moderating effect, as can be seen in the debates about corporate social responsibility, or when protests against GM food are concerned. Still, active consumers pointed to the influence of industry as the most important factor. Regarding their own role, the protecting role of the consumer association has been mentioned, which could be expanded to other issues, such as the eligibility criteria of life insurance companies. However, the consumer association is not a religious, political, or ideological organization. The participants stated that other organizations fulfil a similar role in the decision-making process as the consumer association.

Just as inexperienced public participants did, active consumers mentioned all kinds of actors that have some influence in the decision-making process with respect to gene research. Besides, several participants stressed the influence of commercial interests.

Patient participants from both groups emphasized that, on an individual level, not much influence can be exerted. Rheumatism patients qualified that stance by adding that, as individuals, patient may have some influence via the media, through participation in research studies, by standing up for one's rights, and trough religious and political organizations. One participant stressed the changing relationship between doctors and patients, characterized by increased patient consultation. Another participant was of the opinion that one could have more influence than what was often believed to be the case. However, not everyone agreed, and one participant expressed her conviction that influence is only possible with regard to ethical issues.

> 'For sure, the ethical issues; there are some radio and television programmes where you can give your opinion. That is a kind of example [X] mentioned. It, probably it will be used to test how, to see which way the wind blows …. In those cases, you have some influence. But, furthermore, as I said, there is no company, no doctor, who will ask you what you want as a patient. Be realistic! At the most, the ethical issues, therefore they need us; not to find out what we think about the issue, but to find out which way it is going' (Rheumatism patient, female).

Participants thought that patient associations had some influence, but that they should guard their independence. The most influential factors in gene research are believed to be economical interests. Like the rheumatism patients, the celiac disease patients qualified their initial statement about one's influence by expressing their belief that patient associations have some influence on gene research. However, it was thought that the larger the membership of the association, the more influence it would be able to exert. They also mentioned the independence argument. Finally, they stated that individuals *can* have influence and should empower themselves by actively trying to use it.

> 'Yes, but still, in my view, we shouldn't forget individual influence. Because sometimes it is, sometimes you have to go on as a patient association, but also as an individual. Respond, to newspaper articles, I don't know. Just, be on the alert' (Celiac disease patient, female).

Regarding the role of other actors, patient participants framed their responses mainly in terms of their role as patients and, thus, often referred to medical research. The same range of actors and the same criteria for doing research were mentioned by these participants. Additionally, rheumatism patients emphasized the influence of the pharmaceutical industry and the government, which is withdrawing from research. Celiac disease patients mentioned the pharmaceutical industry as well as the influence of the food industry. Furthermore, both groups mentioned doctors and specialists as having influence on gene research. Concern was also expressed about the growing influence of insurance companies.

Experts, too, reflected upon the sub-theme of influence emanating from their position as experts. Most medical experts thought that some influence was possible, bases on their expert position. However, some experts thought that, as individuals, they were not able to influence gene research since, among other things, decisions are not taken at the national but rather at the European level. According to them, the less citizens trust a given actor, the more influence they want. It was argued that, as individuals patients do not have much influence, although patient associations experience an increasing influence. More and more often collaborations are set up between patient associations and the pharmaceutical industry. However, it was noticed that these partnerships strongly depend on personal relationships, and that significant influence might be possible.

> 'What is interesting, in my opinion, is that recently, more and more coalitions are formed between […] patient associations for rare diseases and the pharmaceutical industry. […] They become more and more, as you could call it, 'partners' when developing new medicines. But […] that influence on decision making depends strongly on personal relations in the medical circuit' (Medical expert, male).

Medical experts mentioned other influential actors, such as patient associations, politicians, the government, the media, lobby groups, and financial institutions. They also argued for increased influence for researchers, governments, and developing countries.

From their position as experts, food experts commented that most of the organizations they work for do have influence, although the influence of some organizations is rather limited. A governmental oversight body has some degree of advisory influence at best. One participant argued that pressure group draw attention to the consequences of gene research, participate in the debate, and guide companies in developing their own opinions with respect to gene research. Furthermore, supermarkets' influence on gene research was believed to be minimal. Developments in gene research are far removed from the day-to-day business of supermarkets, but, in the end, some influence is possible since products have to meet certain requirements. The produce sector is actively involved in gene research, motivated by the environmental standards put in place by the government. Obviously, gene researchers themselves influence gene research. And, according to the experts, the government should play an encouraging role.

*Aspects of decision making*

Inexperienced public participants emphasized that economical interests are an influential factor when doing research and that illegal practices would be encouraged if research would be restricted. Therefore, controlled development would be preferable; laws could play that role. Additionally, the globalisation argument was brought in: research crosses borders. In two groups, participants related the desired influence to trust. One participant stated that it all came down to trust in people, for example, to trust in politicians, who often did not keep their promises in the past.

> 'The question was, to what extent do you have influence on gene research? I wouldn't like to stop it' (Inexperienced public, male).
>
> 'I do not really want to have influence, as I don't want to stop the research yet' (Inexperienced public, female).
>
> 'Well, I don't want to influence gene research since I don't know anything about it. That kind of decisions should be left over to geneticists, not to technicians [like me]' (Inexperienced public, male).
>
> 'I do not agree with you in this matter. It concerns our bodies and our genes, as I said. For me it is too easy to say that if you don't have any knowledge, you don't have an opinion on it. I do think, yes, but, it concerns our genes, our bodies' (Inexperienced public, female).

Availability of information (e.g., in the form of labelling) was an important issue for active consumers as it would enable them to make informed choices.

> 'I think that the consumer association can enforce labelling of products, because the consumer wants this labelling. And consequently, the consumer will decide if he buys the product. Thus, even if authorities tell it is safe, even then the individ-

> ual wants to be able to choose. That is why labelling is very important' (Active consumer, male).

Additionally, they discussed the issue of influence on gene research more in general. They argued that it would be desirable that verifiability, i.e., the control mechanism that is in place for scientific research, would also be applied to industrial research. The complexity of the decision-making process was another issue that was discussed extensively.

> 'Indeed, in my opinion, decisions are not taken in a well-considered way. But, rather, two types of processes take place, let's say, some kind of step-by-step decision making. It all starts with little steps, and at a certain moment in time you are somewhere, and you don't recognize where you are anymore. So, if you ask me who in the Netherlands makes the decisions, I would think it is a combination of politicians, the media, and, around them some stakeholders, including the consumer association. But I can not say more about it, I find this quite difficult' (Active consumer, male).

Of the patient participants, celiac disease participants emphasized transparency and oversight of gene research as important issues. Rheumatism patients thought that the general public was only interested only would like to have influence if one where personally involved. Celiac disease patients agreed that, as individuals, people do not have influence, but they stressed that, if borders are crossed, the Dutch public would stand up and demand societal debate.

> 'If it goes too far, in my opinion, in that case the Dutch people will say "up to here, and no further", then we will hit the streets' (Celiac disease patient, female).

Although the experts acknowledged that they had some degree of direct influence on the decision making about gene research, at the same time, they emphasized that influence on gene research never takes place in a vacuum. Decision making on gene research is a complex process with many actors involved, often in collaboration with industrial actors, and nowadays it takes place in an international context. The experts stated that all actors should play a role and take some responsibility. Medical experts also debated the need for patient associations to guard their independence. Political actors have an oversight role, but, unfortunately, in some projects control only takes place afterwards. One expert emphasized that political actors should rather encourage the diversification of interests. The experts raised the issue that the government, as safeguard for the quality and the safety of products, is limited with regard to what it can accomplish, due to the complex nature of the decision-making process on the matter. Food experts stated more in general that all actors should play a role and take some responsibility regarding gene research. This could be achieved by encouraging research directly by providing financial incentives (e.g., the Ministry of Economical Affairs), by being an active partner, or by getting involved in debates on the issue. According to these participants, consumers, too, should play a role in gene research, and consumer products should be developed that especially benefit consumers, rather than putting products on the market for financial profit. Finally, participants stated that consumers are a powerful force if they would use the influence they have.

> 'Do you think the general public is granted a role where it concerns this type of research?' (Moderator).
>
> 'Yes, in my view for all techniques, as is the case with new product development, you have to think about "what kind of influence it has on the consumer and how the consumer will respond", certainly, if it concerns a new technique. That is always the case when you work at scientific fringes. The word 'gene research' implies it' (Food expert, female).
>
> 'In my opinion, what you said is very important. The consumer is enormously powerful. Then it will become clear if they want it or not' (Food expert, female).

**Table 5.6: Overview of sub-themes and issues of power**

| | General public | Consumers | Patients | | Experts | |
|---|---|---|---|---|---|---|
| | **Inexperienced public** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** |
| *Sub-themes and issues* | | | | | | |
| **Role and influence of participants and other actors in gene research** | | | | | | |
| General public / citizens / as individuals | V | | V | V | V | |
| *- no/ not much influence* | V | | V | V | V | |
| *- (only) via other actors* | V | | | V | V | |
| *- some at the personal level* | V | | | | | |
| *- via elections* | V | | | | | |
| *- not wanted* | V | | V | | | |
| *- wanted* | V | | V | | | |
| *- via politics* | | | V | | | |
| *- via religion* | | | V | | | |
| *- empower themselves* | | | | V | | |
| *- desirable when borders are crossed* | | | | V | | |
| *- when trust is waning* | | | | | V | |
| Consumers association | | V | | V | | |
| *- some influence* | | V | | | | |
| *- protection of consumers* | | V | | | | |
| *- critical attention* | | | | V | | |

**(Table continues)**

**Table 5.6 (continued): Overview of sub-themes and issues of power**

| | General public | Consumers | Patients | | Experts | |
|---|---|---|---|---|---|---|
| | **Inexperienced public** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** |
| *Sub-themes and issues* | | | | | | |
| Patients | | | V | V | | |
| *- some influence* | | | V | V | | |
| *- no/ not much influence* | | | | | V | |
| *- stand up for rights* | | | V | | | |
| *- in ethical issues* | | | V | | | |
| *- involved in doctors' decisions* | | | V | | | |
| *- influence on research by individual patients is undesirable* | | | V | | | |
| Patient associations | V | | V | V | V | |
| *- some influence* | V | | V | V | V | |
| *- guard independence* | | | V | V | V | |
| *- finance/ encourage research* | V | | V | V | | |
| *- partnerships with industry* | | | V | | V | |
| Doctors | V | | V | V | | |
| *- knowledge deficit* | | | | V | | |
| Pressure groups/ environmental groups | V | | | | | V |
| *- attention to problem, no duty to solve it* | | | | | | V |
| *- no open communication* | V | | | | | |
| *- critical attention* | V | | | | | |
| *- temporary delay* | V | | | | | |
| Industry | V | V | V | V | V | V |
| *- food* | V | V | | V | | V |
| *- pharmaceutical* | V | V | V | V | V | |
| *- produce sector* | | | | | | V |
| *- economic interests* | V | V | V | | V | |
| *- most influential* | V | | V | | | |
| *- no open communication* | V | | | | | |
| *- verifiability* | V | | | | | |
| *- should decide* | V | | | | | |
| *- to inform / publish results* | | V | | | | |
| *- growing influence* | | | V | V | | |
| Media | V | V | V | V | V | |
| *- on politicians* | | V | | V | | |
| Politicians | V | V | | V | | |
| *- limited influence* | | | | V | V | |
| *- law* | V | | | | | |
| *- 'to be shaken up'* | | | | V | | |
| *- norms and values* | | | | V | | |
| Government | V | V | V | V | | |
| *- limited influence* | | | | V | V | |
| *- at the European level* | | V | V | V | V | |
| *- oversight role* | | | | | V | |
| *- encourage diversity and non-economic interests* | | | | | V | |
| *- no expert knowledge* | V | | | | | |
| *- withdrawing from research* | | | V | | | |

**(Table continues)**

**Table 5.6 (continued): Overview of sub-themes and issues of power**

| | General public | Consumers | Patients | | Experts | |
|---|---|---|---|---|---|---|
| | **Inexperienced public** | **Active consumers** | **Rheumatism patients** | **Celiac disease patients** | **Medical experts** | **Food experts** |
| *Sub-themes and issues* | | | | | | |
| Researchers / experts / research institutes/ universities | V | V | | V | V | |
| - *within projects* | | | | | V | |
| - *ethicists* | V | | | | | |
| - *exaggerate results* | V | | | | | |
| - *need for verification* | V | V | V | V | | |
| - *too dependent on industry* | V | | | | | |
| - *to inform / publish results* | | V | | | | |
| - *sometimes personal influence* | | V | | | | |
| - *diversity in research needed* | | | V | | | |
| - *long-term effects* | | | V | | | |
| - *slow publishing process* | | | V | | | |
| - *not at the individual level* | | | | | V | |
| - *not to stop research* | V | | | | | |
| - *freedom of research* | V | | | | | |
| Other actors mentioned | | | | | | |
| - authorities | | | | | V | V |
| - lobby groups | | | | | V | |
| - financial institutes | | | | | V | |
| - insurance companies | | | V | | | |
| - developing countries | | | | | V | |
| - supermarkets | | | | | | V |
| - farmers | | | | | | V |
| - health care sector | V | | | | | |
| - educational sector | V | V | | | | |
| **Aspects of decision making** | | | | | | |
| Participation by the public | V | | | | V | |
| Call for debate | V | | | | | |
| All actors need to be involved | | V | | | | V |
| Freedom of choice consumers | | V | | | | V |
| Labelling | | V | | | | V |
| Oversight to ensure transparency | | | | V | | |
| Different influence for food and medicines | V | | | | | |
| Uncontrollable science | V | | | | | |
| Developments continue | V | | | | | |
| Need for responsible production methods and research | | | | | | V |
| Quality products | | | | | | V |
| Development of oversight mechanisms | V | | | | | |
| Need for frontline research | V | | | | | |
| Trust in actors | V | | | | V | |
| Lack of trust in politicians | V | | | | V | |
| Role for consumer association / other pressure groups | | V | | | | |
| Complex decision making process / many actors involved | | V | | | V | |
| Personal interests and relations when making decisions | | | | | V | |
| Decision making diffuse | | V | | | | |
| International context | V | | | | V | |
| Decisions in broader context / with industry | | | | | V | |
| Democratic system influence/ representative democracy | | V | | | V | |

### *5.3.5 Summary of the main results*

In this final section, the main results from the focus group discussions will be summarized. To start with the participants' notions of *communication on gene research* – the first main theme investigated in this study – it was found that, in all groups participants linked *interest* in an issue such as gene research to personal interest or involvement in the issue. Clearly, interests are role-dependent. The inexperienced public participants mentioned the available time and information overload as reasons for limited interests. Furthermore, both inexperienced public participants and experts found that interest in an issue does not automatically imply that people do indeed actively search for information about that issue, although, in general, a higher level of interest leads to more active information-seeking behaviour. People have different needs for information. Active consumers and patients thought that the general public would not be interested and they stated that dissemination of information is only useful when people show interest. Patients regarded dissemination of information as important for keeping people interested. Experts linked interest also to trust in experts, and since the interests of experts do not always coincide with those of citizens, experts need to explain themselves better.

Both inexperienced public participants and active consumers believed that *information coming from all sources may be, and often is, biased.* Especially, information provided by industry was considered to be biased, as it mainly serves commercial interests. That is why they argued that, in order to prevent this bias, oversight mechanisms were required, similarly to the scholarly review systems that are in use in the scientific world, or the provision of information on the wider context of products and production methods. Patients and experts had similar opinions, but labelled them differently. In their eyes, information provided by the media is not fully trustworthy, as they frame information.

All groups stressed the *need for information and knowledge.* However, inexperienced public participants were of the opinion that biased information was a more important sub-theme. They emphasized the need for more information, and argued that this information should be disseminated in popular language, while people with a higher need and level of knowledge should actively search for additional information themselves. Active consumers emphasized the dissemination of information as an important right for citizens, where those who understand the communication process have the duty to disseminate information. At the same time, people should be free to choose for information. And, information is only part of the complex communication process, with communication and knowledge playing significant roles as well. Not surprisingly, patients reported a higher need for information, although this concerns information related to their personal situation. Both patient groups stressed the need for empowerment, but in different ways. Rheumatism patients saw active information dissemination as the preferred communication strategy, while celiac disease patients favoured a more active role for patients themselves. Medical experts thought that different people (and different doctors) have varying needs for knowledge. They argued that, rather than merely *possessing* knowledge, *timely access* to knowledge was the critical issue. Furthermore, experiences with participation activities showed that citizens are able to make decisions about issues without possessing all the relevant knowledge. Food experts believed knowledge to be important for making deliberated of informed decisions. But they also acknowledged that more knowledge about gene research does not automatically lead to greater acceptance of gene research.

A wide variety of *sources of information* were mentioned by inexperienced public participants, who also indicated that they judged many sources to be presenting information only superficially and according to their own criteria (e.g., newsworthiness or economic interest). With respect to possible biases in information, participants suggested several solutions to this problem. For one thing, ensuring that a wide variety of sources are available would enable people to compare information from different sources. Active consumers mentioned open access to information as a solution to this problem. It was suggested that, alternatively, independent organizations could be put in charge of ensuring that balanced information would be available. Both patient groups relied mainly on their patient associations for information, but they differed in the level of faith they had in doctors as reliable sources of expert information. Finally, experts mentioned the issue of the reliability of sources.

A final sub-theme that emerged from the analysis is that of *passive and active elements in the communication process*. Inexperienced public participants, patients, and experts identified the need for transparency and openness in the communication process. According to patients, other interests are sometimes more influential. Together with active consumers, patients pointed to the complexity of this communication process, which might, in their opinion, be improved by paying attention to the public's needs and interests. Patients also emphasized the need to empower themselves in situations where knowledge was not communicated. Medical experts, more than food experts, put more faith in education and dissemination strategies, although their experience with participation activities was good. Food experts stressed the societal need to communicate with the public.

*Trust and power* - The results from the focus group discussions show that trust is an important theme, not only in the eyes of the experts, but also in those of all other participants. All groups emphasized the complex relationship between the public and gene research, or between the public and science more in general. The inexperienced public participants do not have much *trust in actors* such as journalists, politicians, industry, government, and NGOs. They stated that even scientists have their own interests when doing research. However, active consumers and patients also mentioned the same actors as being hard to trust and all participants proposed several control mechanisms for ensuring that trust is gained and maintained. The experts pointed out that people want more influence when actors are less trusted. Surprisingly, medical experts stated that their own faith in industry had diminished.

The inexperienced public participants emphasized a desire for open and transparent communication, as a control mechanism for gaining *trust in general*. For the active consumers, solidarity could be the solution to this problem. From a personal level of involvement in society and societal issues, active consumers have chosen to become members of the Dutch 'Bondsraad', where solidarity is an important issue. Celiac disease patients emphasized their relationships with doctors, and responded to the doctors' (often inadequate) level of knowledge by taking action and empowering themselves. Experts emphasized their experiences with industry, patients and consumers, when pleading for open and transparent communication and involvement of citizens, consumers or patients.

Regarding *the role and influence of participants and other actors on gene research*, all participants discussed this theme, starting from their own role perspectives. Inexperienced public participants did not think that they had any influence on gene research. At best, a limited degree of influence would be possible by deciding whether or not to buy certain products or to cooperate in research. Public consultation, once products have been developed, would be appreciated. Active consumers and patients thought that they had some influence via their own associations as well as through other civil organizations, but, at the individual level, influence was deemed hardly possible. In contrast, experts responded acknowledged that they sometimes had influence on the decision-making process, but they emphasized that this influence was only possible if they co-operated with other actors. All groups stressed the dominant influence of industry, and, therefore, they argued that other actors, such as pressure groups, should play a role as well.

When discussing *aspects of decision making*, inexperienced public participants emphasized the importance of economical interests, and they pointed at controlled development as one way of preventing illegal practices. Active consumers argued that verifiability, for example availability of information by means of labelling, would make research more reliable. Patients referred to this as transparency and control of gene research. They thought that societal debates would emerge if ethical borders were to be crossed. Finally, experts emphasized that influence never takes place in a vacuum, but that decision making about gene research is a complex process in which many actors cooperate and share responsibilities.

## 5.4 Conclusions from the focus group discussions

In this final section, conclusions with regard to the empirical questions will be drawn. (The general conclusions will be discussed in Chapter 7.). To recapitulate, this focus group study was aimed at improving the understanding of the relationship between the public and science, by investigating how publics in various roles perceive the communication process regarding gene research, their own and others' roles and influence, and trust in gene research. Subsequently, the research questions were formulated as follows:

*RQ2a: How do publics in various roles consider the communication process about gene research?*

*RQ2b: How do publics in various roles consider their and others' role in and influence on gene research?*

*RQ2c: How do publics in various roles consider trust related to gene research?*

*Communication about gene research*

The results reveal that the publics, in their roles of inexperienced public, active consumers, patients, and experts hold the same opinions regarding certain aspects of the communication on gene research, while they differ as far as other aspects are concerned. The findings show agreement among all participants with regard to the idea that interest in an issue such as gene research is related to people's personal involvement in the issue, hence, people are not interested in all cases. Within a role, interests can be expressed in various ways, such as requiring a lot of information or not. Furthermore, in all roles, ideas about knowledge, information and communication derived from both models are valued. As it is proposed by the interactive science model, communication entails more than information dissemination, yet, at the same time, as advocates of the deficit model argue; knowledge is still an important factor in this communication. In addition, the complexity of the communication process –where information is often biased or especially framed in a particular way – is emphasized by publics in all roles. The findings provide some insight in the working of communication. In all roles, publics consider transparency and openness important conditions for people's trust in the information.

The findings point also to differences between roles. Publics differ in their opinions about the way the communication process should be shaped. In the role of inexperienced public, people want information to be available, although they would not always use the information. A difference exists between the need for information and the active search for it. The public may be interested but remains passive as it comes to taking initiative to search for information. Active consumers emphasize the need for industry and regulators to listen to the public, and patients want even more. Both groups organize and empower themselves by taking a more active role in the communication process. And, it appears that publics in more organized roles are able to develop skills that enable them to engage in the broader policy and technology debate.

At the same time, the public in the role of experts, point at the need for knowledge and put faith in educating the general public, although they are aware of the need to communicate proactively and of the public's right to get involved.

### *Role in and influence on gene research*

Additionally, the findings reveal that the opinions about the influence on the decision-making process with respect of gene research vary among the different roles as well. The public in the role of inexperienced public holds the belief that any influence is hardly possible, and often not desired. However, the public in the roles of active consumers and patients feel more empowered through involvement in their respective organizations and they think some influence is possible. Somewhat surprisingly, the public in the role of experts modestly place their own influence in the broader context of the complex decision-making process where many other actors also have some influence. All publics consider industry as the most influential actor, despite efforts by the government to regain its influence on the decision-making process, and the fact that all publics emphasize an increased influence for NGOs. According to publics in the role of inexperienced public, active consumers, and patients, economic interests are overwhelming, and, hence, the implementation of control mechanisms – such as controlled development, verifiability of research results (e.g., by means of labelling), and transparency of results – deem crucial for regaining public trust.

In cases where an issue is important for a public, it wants to gain influence on the decision-making process. Membership of organized citizenship shows this, or where ethical borders are being crossed, the call for a broader societal debate rises.

### *Trust in gene research*

Results reveal that trust is an important theme. Publics in all roles emphasize the complex relationship between the general public and gene research – or more in general, between the public and science – due to a lack of trust. Various actors or institutions (e.g., industry, government, the media, and – in the case of celiac disease patients – doctors) are mentioned as being difficult to trust. In connection with these actors, various mechanisms – such as openness of sources and senders' interests, transparent communication, and solidarity – are mentioned as means to rebuild. Experts acknowledge the lack of trust and point out that their own trust in industry has also diminished. They, too, see open and transparent communication, with involvement or participation of citizens, consumers and patients, as the main solution. In conclusion, the publics, in their different roles hold similar opinions about the importance of trust in the relationship between the public and science issues such as gene research. Lack of trust is a strong motivator for the need empowerment. Oversight of research, open and transparent communication, and availability of information are mechanisms they suggest for keeping or restoring trust in science.

In summary, the focus group study provides new insights in the public's relationship with gene research. At this moment, it has to be borne in mind that focus group research is only exploratory in nature (cf. Bates et al, 2005, p. 342), and, hence, that the insights derived from it need to be substantiated by further research. Furthermore, it has to be stressed that focus group discussions based on small and unrepresentative samples cannot be used as the sole empirical evidence to support conclusions (Morgan, 1997). Therefore, the results from this study have been used as input in the development of a quantitative survey in which publics' relationship with science has been further investigated. The results of this survey study will be presented in the next chapter.

# *Chapter 6*

# The publics' participation in gene research
## A survey

*In this chapter the publics' relationship with science is further investigated by means of a survey. First, four different publics are compared with regard to their experience with gene research, and their level of participation in this research. Next, it is investigated how these more passive or more active publics differ in their relationship with gene research. Finally, determinants of passive and active participation are studied. Results are based on a questionnaire survey between a sample of Dutch residents, which was divided into two subsamples: an inexperienced public sample (N=986) and an experienced patient sample (N=41), and a survey between two natural samples of Dutch celiac disease patients (N=68) and experts in gene research (N=45). The analysis revealed that significant differences exist between the groups with regard to their degree of passive and active participation in gene research. Furthermore, more active publics (experts, celiac disease patients and experienced patients) differed from the more passive public (inexperienced public) in their relationship with gene research, except for factors where expertise in gene research was not required (e.g., in their general opinion about citizen's participation). Remarkably, for certain factors, patients responded like the experts did. Finally, the findings revealed that information-seeking behaviour, relative knowledge, and education level were predictive for passive participation, while relative knowledge and gender were predictors of active participation.*

### 6.1 Introduction and research questions

Like the studies prescribed in the previous chapters, this study was aimed at gaining a better understanding of publics and their relationship with gene research. In the focus group discussions differences between publics in various roles were revealed with respect to their willingness to participate in gene research, their opinions about the role of scientific knowledge, their opinions about the communication and information on gene research and their trust in and influence on gene research. However, focus group methodology only allowed for identifying these differences. The aim of the present study was to see whether (these) differences can be found for larger populations. Again, publics in various roles were studied (i.e. inexperienced general public, experienced patients, celiac disease patients and experts in the field of genomics). The following specific research question was formulated:

*RQ3:* *How do publics, passively or actively participating in gene research, differ in their relationship with genomics?*

Based upon this question and applied to genomics, the following empirical research questions were formulated for this study:

*RQ3a:* *How do levels of participation in gene research (passive or active) differ between the selected publics?*
*RQ3b:* *How do these publics differ in their opinions about gene research, communication and trust?*
*RQ3c:* *Which factors determine passive and active participation?*

First, it was examined whether the existence of the four publics with different levels of participation (passive or active) in gene research could be confirmed. Second, the four publics' opinions about gene research, communication and trust were analyzed. Finally, it was examined which factors were predictive for active and passive participation.

In the next section (6.2) details of the survey method will be described. In the following section (6.3) results from the survey will be presented, while in the last section (6.4) conclusions will be drawn.

## 6.2 Design of the survey

*Samples and participants*

In the winter of 2006/2007, 6266 persons, between 18 and 65 years old, and representative for the Dutch population, were approached via an Internet panel of a professional marketing research agency.[1] In total, 1380 people started the online questionnaire, and 1056 respondents completed it (response rate = 17%). Additionally, members of two 'natural' groups were approached and asked to take part in the survey. First, members of the Dutch celiac disease patients' association[2] were asked to fill out the questionnaire by a call for participation and a link to the online questionnaire on the website of this association. Of the 294 people that visited the website, 68 respondents completed the questionnaire

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[1] The agency is called Motivaction.

[2] Celiac disease is gluten intolerance. Patients need to keep a strict diet and until today the disease cannot be treated with medicines. The celiac disease patient association is involved in several genomics research projects. More research at the gene level of the patient can provide insight in the disease. Also food genomics can contribute to a better life. This background made celiac disease patients an interesting sample to include.

(response rate = 23%). Second, experts in genomics research were recruited by sending them an email with the link to the questionnaire via their contact persons at the national research program of the national science foundation (NWO-MCG). Included were experts that joined one of the Centres of Excellence of the National Genomics Initiative in the Netherlands.[3] All in all, 49 experts completed the questionnaire. The two natural groups were asked questions related to gene research, while respondents of the general public were questioned about gene research and food and health issues.

First, respondents who indicated to have experience with gene research trough their work or their education were excluded from the general public group (N=39). Next, the general public group was divided into two sub samples: an inexperienced public sample and a sample of respondents with experience in gene research as a patient. Furthermore, respondents from the expert sample who indicated to have no experience with gene research were excluded. The remaining 1140 questionnaires were used for the analysis. They consisted of questionnaires from 986 inexperienced members of the general public (I -inexperienced public), 41 members of the general public with experience in gene research as a patient (II - experienced patients), 68 celiac disease patients (III - celiac disease patients), and 45 experts (IV - experts).

*Measurement instrument*

The survey questionnaire used in this study (see Appendix 5), consisted of measures that were based on the theoretical concepts of *passive and active publics*, *scientific knowledge*, *information and communication*, and *trust*. Related to the concept of *passive and active publics* were measures of participation, namely the respondents' level of passive and active participation in gene research, and the respondents' opinion on citizen's involvement in gene research. The concept of *scientific knowledge* was included by measures of self-reported relative knowledge of gene research. Related to the concept of *information and communication* were measures of information handling, i.e., information need and information-seeking behaviour. The concept of *trust* was included by measures of trust in general, by measures of trust in specific organizations or groups of people, and by measures of influence of organizations or groups of people in setting limits to gene research. Furthermore, measures of respondents' perceptions of food and medical issues, as well as

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[3] The research of these 13 centers is funded by the Dutch National Science Foundation (NWO-MCG). The total number of experts who join the centers is not exactly known, since experts may be members of more than one center at the same time. Besides, checking of the mail to be sent to experts was difficult for several reasons: not all centers wanted to co-operate when requested to forward the e-mail; some centers only provided some of the experts' names; and, when forwarded, a copy of the mail was not always sent to the researcher. The two centers focusing on societal aspects of genomics were excluded.

their interests in medical and food examples were included in the questionnaire. A section on demographics, i.e., gender, level of education, age, social involvement and political involvement, completed the survey questionnaire. Certain measures were derived from the literature, while others were based on the results of the document analysis and the focus group studies (Chapters 3 and 4, respectively), or were especially designed for the current study. A pilot study preceded the survey and guided the construction of the measures to be used in the final analysis. Master's students (from Biology and Communication Sciences) filled out the questionnaire (N=70). Based on reliability analysis and factor analysis the final construction for the measures was made.

To ensure that respondents understood what was meant by 'gene research', a short explanation was given at the start of the questionnaire. Only the Dutch term 'genenonderzoek' was used when referred to gene research. Other general terms were not used in the questionnaire. On the one hand, the term 'gene research' is necessarily somewhat general since questionnaires are never able to cover all aspects of a phenomenon, but this term is probably better known than an even more general term like 'genomics'. On the other hand, the use of more specific subcategories would perhaps have confused respondents, although some patients and experts probably would have appreciated it.

Table 6.1 shows reliability analysis of the measured scales for the four groups, reported in Cronbach's alpha. The concept of *participation* was based on five items in which respondents could indicate their level of participation in gene research. The items were derived from Arnstein's (1969) ladder of participation in which the level of participation ranges from no participation to full decision-making power. Respondents could specify their answers on a 4-point Likert-type scale ranging from 1- "no, never" to 4- "yes, often". Factor analysis revealed two sub scales, which were labelled 'passive' and 'active participation'. *Passive participation* consisted of three items in which respondents could indicate if they had passively participated in gene research, ranging from reading, hearing, or watching information on gene research to talking about information on gene research (e.g., "Before you filled in this questionnaire, did you ever talk to someone about gene research?"). Reliability analysis indicated acceptable or good internal consistency for passive participation within all groups. *Active participation* included two items in which respondents could indicate their active participation behaviour regarding gene research (e.g., "Before you filled out this questionnaire, did you ever attend a meeting, such as a lecture, or a public hearing, on gene research?"). Correlations between the two items were high for the inexperienced public sample, the experienced patient sample, and the expert sample, and acceptable for the celiac disease patient sample.

*Opinion on citizen's participation* is based on a question about the judgment of citizen's participation in the GM Nation Debate in Poortinga's et al. (2003) study and adapted to the Dutch case. The construct existed of five items in which respondents could indicate their agreement on government efforts to involve citizens into decision making about the limits of gene research (e.g., "Involving citizens in decision making about limits of gene research influences governmental decisions with regard to this issue."). Each item was rated on a 5-point Likert-type scale, ranging from 1- "strongly disagree" to 5- "strongly agree". Two negatively phrased items were reverse-coded, thus higher scores indicated higher agreement. However, factor analysis showed one conflicting item, and, therefore, this item was excluded from the analysis. Reliability analysis indicated acceptable or good internal consistency of the construct for all samples, except for the experienced patient sample for which low reliability was reported.

*Relative knowledge of gene research* - was measured by two items asking for respondents' self-reported knowledge of gene research on a 3-point scale, ranging from 1- "know more" to 3-"know less" (e.g., "In comparison with other people in my surroundings, I am inclined to think that regarding gene research I …"). The items were recoded, thus a higher score indicated more self-reported knowledge. High correlations between the two items were reported for all samples.

*Information handling* - was included as an indication of the way communication takes place, and was measured by asking respondents how they behave with regard to information on gene research. Two sub scales were developed, based on the literature on information sufficiency and information-seeking and information-processing behaviour (Griffin, Dunwoody & Neuwirth, 1999; Grunig, 1989; Ter Huurne & Griffin, 2007), and adapted to the situation of gene research. Three items in the sub scale *need for information* assessed the need for information on gene research (e.g., "In order to develop an opinion on gene research, I need much information."). Three items in the sub scale *seeking information* assessed the information-seeking behaviour dimension (e.g., "In cases of societal debate regarding gene research I search for information on the issue."). The items were measured on a 5-point Likert-type scale ranging from 1- "strongly disagree" to 5- "strongly agree". Factor analysis revealed single factors. Reliability analysis indicated good internal consistency for need for information for all groups, except for the expert group. Internal consistency for search for information was acceptable or good within all groups.

*Trust* - has been conceptualized in other studies as consisting of several dimensions, such as social trust and institutional trust (Earle & Cvetzovich, 1995; Sztompka, 1999). In this study, respondents were asked to give their judgments of *general trust* and *trust in specific organizations or groups of people*. Respondents were asked in which situations they trusted organizations or groups of people in general (*general trust*, five items, e.g., “I trust organisations or groups of people, when they make clear which interests they have in gene research.”). Factor analysis revealed one factor. Reliability analysis indicated high internal consistency within all groups. Respondents were asked to indicate how much they trusted six specific groups of organizations or groups of people to be honest about gene research (*trust in organisations or groups of people*, six single items, including “commercial organisations such as industrial producers and supermarkets”, and “friends and family”). They could specify their agreement on a 5-point Likert-type scale, ranging from 1- “no trust at all” to 5- “very much trust”.

*Influence in decision making* - From a democratic rationale it is expected that citizens set great store to influence on decision making. As Arnstein (1969), and recently Poortinga and Pidgeon (2003) indicated, public participation is related to power, amongst other things by influence on the decision-making processes, which is also related to trust. Therefore, it was asked how much influence each of the following organizations or groups of people should have in determining the limits of gene research (e.g., “Societal organizations such as environmental organizations, consumer organizations, or patient organizations”). Based on results from Chapter 5, and earlier work from Poortinga and Pidgeon (2003), influence of the respondent self with friends and family was included, and it was expected that people agree with the idea of public involvement, but that the willingness to get personally involved is not very high. The answers could be given on a 5-point Likert-type scale, ranging from 1- “no influence at all” to 5- “very much influence”.

*Perception of gene research* - is based on previous Dutch research with regard to gene research (Pin & Gutteling, 2006), and adapted to the current situation. Three items measured *perception of food issues*, three other items measured *perception of medical issues*. Respondents were asked to indicate their positive or negative judgement of gene research developments (e.g., “The use of gene research to make plants and food products healthier for human beings.”). Each item is rated on a 5-point Likert-type scale, ranging from 1- “very negative” to 1- “very positive”. Reliability analysis indicated high internal consistency for perception of food issues within all groups. For perception of medical issues reliability analysis showed acceptable or good internal consistency, except for the celiac disease patient group, for which low reliability was reported. Factor analysis revealed single factors for both perceptions of food issues, and perceptions of medical issues.

*Interest in food and medical issues of gene research* - was also based on previous Dutch research regarding gene research (Pin & Gutteling, 2006), and adapted to the current situation. Three items measured *interest in food issues*, whereas another three items measured *interest in medical issues* (e.g., “I am very interested in the development of genetic tests to determine hereditary diseases.”). Items were rated on a 5-point Likert-type scale, ranging from 1- “completely disagree” to 5-“completely agree”. Within all groups, reliability analysis indicated high internal consistency for interest in food issues as well as for interest in medical issues. Factor analysis revealed single factors for both interest in food issues, as well as for interest in medical issues.

**Table 6.1: Reliability of measured scales per group (in Cronbach's Alpha)**

| | | General public sample | | Natural samples | |
|---|---|---|---|---|---|
| | | **I- Inexperienced public (N=986)** | **II- Experienced patients (N=41)** | **III- Celiac disease patients (N=68)** | **IV- Experts (N=45)** |
| | *# items (min-max)* | | | | |
| Passive participation | 3 (1-4) | .74 | .76 | .76 | .79 |
| Active participation[a] | 2 (1-4) | .40** | .43** | .28* | .66** |
| Opinion on participation citizens | 4 (1-5) | .71 | .59 | .82 | .68 |
| Self-reported related knowledge of gene research | 2 (1-3) | .68** | .48** | .64** | .67** |
| Information need | 3 (1-5) | .78 | .79 | .78 | .55 |
| Information seeking | 3 (1-5) | .74 | .80 | .63 | .78 |
| General trust in organizations | 5 (1-5) | .92 | .92 | .87 | .77 |
| Perception food issues | 3 (1-5) | .87 | .93 | .90 | .91 |
| Perception medical issues | 3 (1-5) | .80 | .67 | .59 | .69 |
| Interest food issues | 3 (1-5) | .85 | .79 | .79 | .88 |
| Interest medical issues | 3 (1-5) | .94 | .81 | .76 | .85 |

[a] Correlation coefficients (Spearman's rho) are reported when scales consist of two items; * $p < 0.5$; **$p<0.1$; Not all data were normally distributed; in these cases Spearman's rho, a non-parametric statistic, was used (cf. Field, 2005).

Although within the smaller samples some scales reported low reliability (between .55 and .59), it was decided to maintain these scales, since, in the larger inexperienced public sample reliability of these scales was satisfactory.

*Demographics* - The respondents demographics – gender, educational level, and age –were taken into account, as well as social involvement and political involvement (one item each, on a 5-point Likert-type scale, ranging from 1- "not at all involved" to 5- "very much involved"; taken together as social involvement, with reported correlations (Spearman's rho) of r = .33**; .41**; .24*; .47** for the samples I – IV respectively).

### *Analysis*

All statistics were performed with the Statistical Package for Social Science (SPSS) 12.0 for Windows. Since for some measurements single items were used, relationships within samples between the measurements were explored by means of Spearman's correlation analysis. Additionally, data were analyzed using univariate analysis of variance (ANOVA) supplemented by post hoc tests, to test whether the four publics differed regarding their level of participation, and how the four publics differed. In spite of the fact that homogeneity of variance (Levenes' test) showed significant results for some measurements[4], most variances of variables were homogeneous[5], and therefore ANOVAs were used, and effect sizes ω are reported (Field, 2005).[6] Furthermore, for *active participation*, also nonparametric test results, Kruskall-Wallis tests for differences, and Jonckheere-Terpstra tests for the direction of these differences were reported, since results for this construct were not normally distributed. Finally, in order to find determinants of passive and active participation hierarchical multiple regression analyses were performed.

## 6.3 Results

### *6.3.1 Characteristics of the samples*

The sociodemographic characteristics of the four publics in the study are summarized in Table 6.2. In the inexperienced public group, 48% males and 52% females participated ($\chi^2(1) = 0.5$, ns). Respondents ranged in age from 18 to 65 years, with a mean of 46 years (SD=12.8). In total, 34% of the participants indicated to have a higher level of formal education, 47% an intermediate, and 19% a lower level of formal education. The experienced patient group consisted of 42% males and 59% females ($\chi^2(1) = 1.1$, ns). Respondents ranged in age from 20 to 65 years, with a mean of 48 years (SD=12.6). Regarding their level of education, 42% of the respondents reported to have a higher level of formal education, 42% reported an intermediate level, and 17% reported a lower level of formal education. Data for the two natural groups revealed that, in the celiac disease patient sample, the vast majority of respondents (91%) were female, while only 9% were male ($\chi^2(1) = 45.0$, $p<.001$).[7] Respondents in this group varied in age from 19 to 79 years, with a mean of 42 years (SD=12.1). In total, 66% of the respondents reported to have a higher level of formal education, 32% reported an intermediate level of formal education, and 2% a lower level. Respondents in the expert group were predominantly male (82%) while 18% were female ($\chi^2(1) = 19.3$, $p<.001$), and ranged in age from 24 to 61 years with a mean of

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[4] The following measurements showed significant results from Levene's test for homogeneity of data: passive participation, active participation, need for information, trust in organizations or groups of people in general, trust in independent researchers, influence of independent researchers, interest in food issues, perception of medical issues and self-reported relative knowledge. For the decision to use univariate analysis of variance (ANOVA) I refer to the discussion about conservative versus liberal views on analyzing statistical data (cf. Knapp, 1990).

[5] When sample sizes are unequal, ANOVA analysis is not robust to violations of homogeneity of variance. However, in those cases that homogeneity of variance is violated, Welch F statistics, which are robust to violations of homogeneity of variance, are reported (Field, 2005).

[6] Effect size measure ω (omega) can be compared to Pearson's r, but the measure makes an adjustment for the fact that the effect size r is estimated (Field, 2005).

[7] The fact that twice as many women than men suffer from celiac disease partly accounts for this difference (Van de Kant & Gremmen, 2004).

40 years (SD=10.1). All respondents (100%) indicated to have a higher level of formal education. For all four groups together, significant differences between the groups were found for gender ($\chi^2(3) = 62,9$, $p<.001$), educational level ($\chi^2(4) = 106.0$, $p<.001$), and age ($F\ (3, 1140) = 9.3$, $p<.001$). No differences were found for social involvement ($F\ (3, 1140) = 3.33$, ns) and political involvement ($F\ (3, 1140) = .77$, ns). Thus, the two groups derived from the general public sample are representative for the Dutch population regarding gender, but were slightly higher educated and less often from a single-person household (Statistisch Jaarboek CBS, 2007).[8]

**Table 6.2: Characteristics of the samples**

| | Dutch Population[a] | General public sample | | Natural samples | |
|---|---|---|---|---|---|
| | | **I- Inexperienced public (N=986)** | **II- Experienced patients (N=41)** | **III- Celiac disease patients (N=68)** | **IV- Experts (N=45)** |
| | *%* | *%* | *%* | *%* | *%* |
| **Gender** | | | | | |
| Male | 49.5 | 48.4 | 41.5 | 8.8 | 82.2 |
| Female | 50.5 | 51.6 | 58.5 | 91.2 | 17.8 |
| **Education** | | | | | |
| Higher | 25.1 | 34.0 | 41.5 | 66.2 | 100.0 |
| Intermediate | 41.0 | 47.1 | 41.5 | 32.4 | 0.0 |
| Lower | 33.4 | 19.0 | 17.1 | 1.5 | 0.0 |
| **Age** | | | | | |
| < 20 years | 24.3 | 2.2 | - | 1.5 | - |
| 20 – 39 | 26.9 | 26.7 | 26.8 | 50.0 | 44.4 |
| 40 – 64 | 34.5 | 71.1 | 73.2 | 45.6 | 55.6 |
| 65 – 80 | 10.7 | - | - | 2.9 | - |
| > 80 years | 3.6 | - | - | - | - |
| **Household type** | | | | | |
| One-person household | 35.0 | 13.2 | 12.2 | 8.8 | 17.8 |
| Multi-person household | 65.0 | 82.3 | 85.4 | 91.2 | 82.2 |
| Missing | | 4.6 | 4.4 | | |

[a] Taken from the Statistisch Jaarboek 2007, Centraal Bureau voor de Statistiek (2007).

The participants from the two 'natural groups' were younger, and more often highly educated, compared to the general public groups and to the Dutch population as a whole. Participants from the group of celiac disease patients were predominantly female, whereas participating experts were predominantly male. In spite of the differences in gender and educational level in both natural groups, it was decided not to correct for gender or educational level for two reasons. First, the celiac disease patient group and the experts group were considered to be naturally formed groups, which would be unrealistic to correct for. Second, the results would be too much deflated due to the small number of male respon-

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[8] Respondents who are more highly educated are often overrepresented in this type of survey research.

dents in the celiac disease group (6 out of 68 respondents) and the small number of female respondents in the expert group (8 out of 45 respondents), together with the fact that all experts were highly educated.

### *6.3.2 Levels of participation in gene research*

Table 6.3 shows the levels of active and passive participation for the four groups in the study. As expected, large and significant differences were found between the four groups for passive participation ($F$ (3, 1136) = 194.59, $p<.001$, $\omega = .58$) as well as for active participation ($F$ (3, 1136) = 442.21, $p<.001$, $\omega = .72$). The levels of both passive and active participation were lowest in the inexperienced public group, and highest in the expert group, while the two patient groups ranked in between and were not significantly different from each other (I < II, III <IV).[9] As expected, the more experienced group, i.e. the experts, reported the highest level of both passive and active participation. The two patient groups both reported quite a high level of passive participation, but a rather low level of active participation, while the inexperienced public reported hardly any active participation in gene research, and the lowest level of passive participation (see also Figure 6.1).

**Table 6.3: Means, Standard Deviations, and differences between samples for passive and active participation (ANOVA)**

| | General public sample | | Natural samples | | | | |
|---|---|---|---|---|---|---|---|
| | **I – Inexperienced public (N=986)** | **II – Experienced patients (N=41)** | **III- Celiac disease Patients (N=68)** | **IV- Experts (N=45)** | **ANOVA** | **Effect (ω)** | ***Post hoc tests (Hochbergs GT2)*** |
| | M (SD) | M (SD) | M (SD) | M (SD) | *F* (3, 1136) | | |
| Passive participation[a] | 1.56 (.51) | 2.07 (.62) | 2.19 (.70) | 3.37 (.64) | 194.59*** | .58 | I< II, III< IV |
| Active participation[ab] | 1.03 (.20) | 1.18 (.40) | 1.26 (.49) | 2.62 (.87) | 442.21*** | .72 | I< II, III< IV |

[a] When measurements of homogeneity of variance are broken, Welch F statistics and Games-Howell post hoc analysis are reported; [b] Results for active participation showed that data are not normally distributed; therefore additionally a nonparametric Kruskall-Wallis test was conducted to look for differences between samples (H (3) = 433.90***), and a Jonckheere-Terpstra test was done to signal trends (z = 17.48***, r = .52). Since, in both (parametric and nonparametric) tests large effects were found, Welch F statistics were reported. * p<.05, **p<.01, ***p<.001.

Further analysis of the answers on the single items that measure passive and active participation (see Table 6.4) showed that a considerable percentage of the inexperienced public group never even passively participated in gene research, that is, never read (27.2%), or searched information on gene research (77.5%) or talked about the issue (56.9%). These percentages were much lower for both the patient groups and the expert group. Less than

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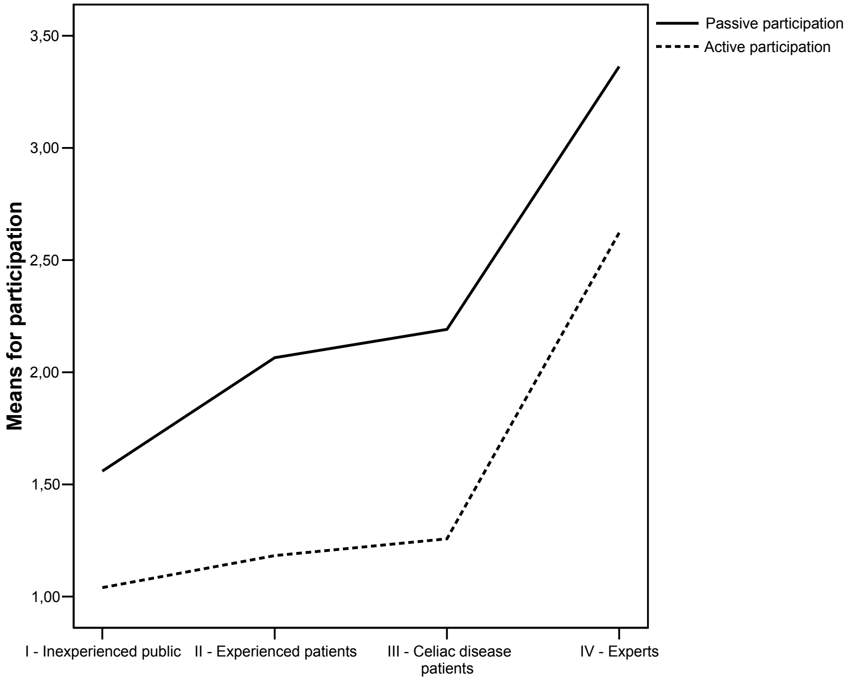
[9] Contrast tests showed similar differences between the samples. Contrary to post hoc analysis contrast tests assume differences between samples, and therefore, one-sided tests can be conducted which have more statistical power (Field, 2005). The results from post hoc analysis were reported here in order to facilitate the comparison of these results with those of the other measurements.

1% of the respondents of the inexperienced public group indicated to have actively participated in gene research on a regular basis by attending a public meeting on gene research or by participating in discussions about gene research. Only 2-3% reported to have ever done so. This stands in stark contrast to participation patterns of the experts, the far majority of whom indicated to have attended a public meeting on gene research sometimes (31.1%), or regularly and often (64.4%) or indicated to have actively participated in discussions sometimes (35.6%) or either regularly or often (31.1%) (data not shown).

**Figure 6.1: Means for passive and active participation**



Both patient groups scored in between. Of the experienced patients, none (0%) attended public meetings, while only 2.4% participated actively in discussions either regular or often in discussions. These findings were very similar to those of the celiac disease patients. Of these respondents, 4.4% attended public meetings regularly or often, and 2.9% participated actively in discussions either regularly or often. However, in contrast to what was the case in the inexperienced public sample, a much higher percentage of the respondents of both patient groups answered that they sometimes attended a public meeting (22% of the experienced patients and 25% of the celiac disease patients) or sometimes actively participated in discussions (7.3% of the experienced patients, and 7.4% of the celiac disease patients).

**Table 6.4: Passive and active participation in the inexperienced public sample**

| | **No, never (%)** | **Yes, sometimes (%)** | **Yes, regularly and yes, often (%)** |
|---|---|---|---|
| **Before you filled out this questionnaire, did you ever** | | | |
| *(Passive participation)* | | | |
| - read information on gene research | 27.2 | 56.5 | 16.3 |
| - search for information in the library or on the Internet | 77.5 | 18.7 | 3.9 |
| - talk to someone about gene research | 56.9 | 37.8 | 5.3 |
| *(Active participation)* | | | |
| - attend a public meeting on gene research | 97.4 | 2.0 | .6 |
| - participate actively in discussions about gene research | 96.1 | 3.1 | .8 |

### *6.3.3 Differences between the groups*

Table 6.5 shows the mean scores, the standard deviations and the differences between the four groups with regard to their opinion about citizen's participation, their self-reported relative knowledge, their information need and their information-seeking behaviour.

**Table 6.5: Means, standard deviations, and differences between groups (ANOVA) for citizen's participation, relative knowledge, information need and information seeking**

| | *General public samples* | | *Natural samples* | | | | |
|---|---|---|---|---|---|---|---|
| | **I – Inexperienced public (N=986)** | **II – Experienced patients (N=41)** | **III- Celiac disease Patients (N=68)** | **IV- Experts (N=45)** | **ANOVA** | **Effect (ω)** | ***Post hoc tests (Hochbergs GT2)*** |
| | M (SD) | M (SD) | M (SD) | M (SD) | *F* (3, 1136) | | |
| Citizen's participation | 3.32 (.82) | 3.77 (.73) | 3.63 (.84) | 3.58 (.79) | 7.78*** | .13 | I, IV< III, II |
| Relative knowledge | 1.89 (.53) | 2.34 (.48) | 2.35 (.54) | 2.98 (.15) | 84.12*** | .42 | I< II, III< IV |
| Information need[a] | 4.10 (.81) | 4.33 (.71) | 4.74 (.50) | 4.42 (.53) | 16.81*** | .20 | I< II, IV< III |
| Information seeking | 3.25 (.92) | 3.78 (.90) | 3.93 (.72) | 4.03 (.79) | 24.91*** | .24 | I< II, III, IV |

[a] When measurements of homogeneity of variance are broken, Welch F statistic and Games-Howell post hoc analysis are reported; * p<.05, **p<.01, ***p<.001.

*Citizens' participation* - ANOVA tests indicated significant differences with a small effect between samples for respondents' *opinion on participation of citizens* (*F* (3, 1136) = 7.78, p<.001, ω = .13). The inexperienced public group considered citizens' participation less important than the experienced public group and the celiac disease patient group did, but their opinion was not significantly different from that of the expert group (I, IV < III, II).

*Relative knowledge* – ANOVA test results showed significant differences and a medium effect between groups (*F* (3, 1136) = 84.14, p <.001, ω = .42), with the inexperienced public having less knowledge than the patients and the experts (I < II, III < IV).

*Information handling* – Results indicated that the groups differed regarding their handling of information, as for both *need for information* (*F* (3, 1136) = 16.81, p <.001, ω = .20) and *information-seeking behaviour* (*F* (3, 1136) = 24.91, p <.001, ω = .24) significant differences with a small effect were shown. Celiac disease patients reported the highest need for information, while the inexperienced public reported the lowest. The need for information was the same for experienced patients and the inexperienced public, while celiac disease patients required significantly more information than experts did (I < II, IV < III). Furthermore, results showed that the inexperienced public group searched for information about gene research significantly less often than the other groups did (I < II, III, IV) (see also Appendix 6).

### *Trust*

Table 6.6 shows the mean scores, the standard deviations and differences between the four groups with regard to their general trust and their institutional trust and influence.

*Trust* – Results showed differences with a small effect between the groups regarding respondents' trust in organizations and groups of people in general (*F* (3, 1136) = 18.96, p <.001, ω = .21). Post hoc analysis revealed that this general trust was the lowest for the inexperienced public and the experienced patients, and it was the highest for the experts and the celiac disease patients (I, II < IV, III).

*Institutional trust and influence in decision making* – Since in the literature trust and power are often presented as being related (Hansen, 2005), a closer look was taken at the correlations for trust in organizations and the desired role in and influence on decision making of these organizations. As shown in Table 6.7, most measurements of trust and influence in all groups were significantly correlated. Therefore, trust in certain organizations or groups of people and influence in decision making for the same organizations or groups of people were compared with each other.

For all groups, trust in organizations or groups of people was the lowest for commercial organizations, and the highest for independent research. However, between the groups differences with small effects existed for trust in commercial organizations (*F* (3, 1136) = 4.00, p <.01, ω = .09) as well as for trust in independent research (*F* (3, 1136) = 11.09, p <.001, ω = .16). Post hoc analysis showed that trust in commercial organizations was rated equally low by the inexperienced public, the celiac disease patients, and the experienced patients, but was rated significantly higher by the experts (I, III, II < IV). The inexperienced public and the experienced patients trusted independent research the least while celiac disease patients trusted independent research the most. Celiac disease patients did not differ significantly from experts in this respect (I, II < IV, III).

**Table 6.6: Means, standard deviations, and differences between groups for trust and influence (ANOVA)**

| | General public sample | | Natural samples | | | | |
|---|---|---|---|---|---|---|---|
| | **I – Inexperienced public (N=986)** | **II – Experienced patients (N=41)** | **III- Celiac disease patients (N=68)** | **IV- Experts (N=45)** | **ANOVA** | **Effect (ω)** | ***Post hoc tests (Hochbergs GT2)*** |
| | M (SD) | M (SD) | M (SD) | M (SD) | *F* (3, 1136) | | |
| *General trust* | 3.44 (.79) | 3.74 (.82) | 4.05 (.68) | 3.92 (.55) | 18.96*** | .20 | I, II< IV, III |
| *Trust in:* | | | | | | | |
| commercial organizations | 1.96 (.77) | 2.05 (.71) | 1.97 (.81) | 2.36 (.77) | 4.00** | .09 | I, III, II< IV |
| friends | 3.01 (.99) | 3.15 (.82) | 3.24 (.97) | 3.13 (.89) | 1.45$^{ns}$ | - | - |
| NGOs | 3.33 (.93) | 3.32 (.93) | 3.71 (.83) | 2.89 (.83) | 7.15*** | .13 | IV< I, II< III |
| commercial researchers | 2.79 (.93) | 2.93 (.93) | 2.96 (.94) | 3.33 (.83) | 5.65*** | .11 | I, II, III< IV |
| independent researchers[a] | 3.69 (.96) | 3.71 (1.08) | 4.29 (.69) | 4.11 (.89) | 11.09*** | .16 | I, II< IV, III |
| government | 2.74 (.92) | 2.80 (.87) | 3.21 (.89) | 3.40 (.84) | 12.32*** | .17 | I, II< III, IV |
| *Influence in decision making by:* | | | | | | | |
| commercial organizations | 2.16 (1.00) | 2.17 (1.02) | 1.85 (1.00) | 2.58 (.87) | 4.73** | .10 | III, I, II< IV |
| myself, friends | 2.79 (1.12) | 3.32 (1.17) | 3.21 (1.02) | 2.91 (.93) | 5.76*** | .11 | I, IV< III, II |
| NGOs | 3.49 (1.00) | 3.27 (1.05) | 2.87 (.96) | 3.47 (.73) | 3.98** | .08 | II< I, IV< III |
| commercial researchers | 3.00 (1.02) | 3.15 (1.04) | 3.32 (1.10) | 3.56 (.73) | 6.16*** | .12 | I, II, III< IV |
| independent researchers[1] | 3.78 (1.02) | 3.83 (1.20) | 4.29 (.81) | 4.20 (.69) | 7.68*** | .13 | I, II< IV, III |
| government | 3.35 (1.07) | 3.17 (1.14) | 3.76 (1.05) | 3.76 (1.00) | 5.45*** | .11 | II, I, IV< III |

[a] When measurements of homogeneity of variance are broken, Welch *F* statistic and Games-Howell post hoc analysis are reported.
* p <.05, **p <.01, ***p <.001.

**Table 6.7: Correlations (Spearman's rho) for institutional trust and influence**

| | General public samples | | Natural samples | |
|---|---|---|---|---|
| | **I – Inexperienced public (N=986)** | **II – Experienced patients (N=41)** | **III- Celiac disease patients (N=68)** | **IV- Experts (N=45)** |
| Commercial organizations | .50** | .60** | .31* | .22 |
| Myself, friends and family[a] | .25* | .44** | .22 | .19 |
| NGOs | .52** | .57** | .37** | .25 |
| Commercial researchers | .40** | .13 | .55** | .40** |
| Independent researchers | .61** | .80** | .42** | .49** |
| Government | .41** | .63** | .43** | .35* |

[a] Respondents were asked in this item about influence of themselves, friends, or family, and about trust in friends and family.
* p<.05, **p<.01, ***p<.001.

The data revealed the same pattern for the influence on the decision making of commercial organizations (*F* (3, 1136) = 4.73, p <.01, ω = .10) and for independent research institutions (*F* (3, 1136) = 7.68, p <.001, ω = .13), with significant differences with small effects between the groups. All groups wanted commercial organizations to have the least influence, and independent researchers the most. However, the different groups varied in their views on the influence of commercial organizations. Celiac disease patients, followed by the inexperienced public and the experienced patients, wanted commercial organization to have the least influence, while the experts gave the most positive judgment (III, I, II < IV). Additionally, both the inexperienced public and the experienced patients desired the lowest influence for independent research organizations, while celiac disease patients and experts wanted these to have the most influence (I, II < IV, III).

The groups did not differ significantly in their judgment of trust in friends and family (*F* (3, 1136) = 1.45, ns). However, regarding the desired influence on decision making by the respondents themselves, their friends and their family, the groups differed significantly (*F* (3, 1136) = 5.76, p <.001, ω = .11). The inexperienced public and the experts wanted these people to have the least influence, while both patient groups wanted them to have the most influence (I, IV < III, II).

The groups differed significantly in the level of trust in NGOs, such as environmental organizations, consumer associations and patient organizations (*F* (3, 1136) = 7.15, p <.001, ω = .13). The trust in NGOs was the lowest in the expert group and the highest in the celiac disease patient group, with the inexperienced public and the experienced patients ranking in between (IV < I, II < III). The groups differed less in their opinions about the desired influence in decision making (*F* (3, 1136) = 3.98, p <.01, ω = .08). These differences can be attributed to disagreement between the four groups with respect to the desired degree of influence for NGOs. Celiac disease patients wanted NGOs to have the most influence, while the experienced patients wanted them to have the least. The experts and the inexperienced public occupied an intermediate position with respect to this issue (II < I, IV < III).

A small effect between the groups was revealed for their opinion about trust in researchers working for government, industry and environmental organizations (*F*(3, 1136) = 5.65, p <.001, ω = .11). These researchers were least trusted by the inexperienced public, while both patient groups showed more trust in these researchers, and the experts trusted them the most (I, II, III < IV). Surprisingly, the mean scores for trust in commercial organizations were .8 to 1.3 points lower than the mean scores for trust in researchers that are independent or work for universities. The inexperienced public, followed by the experienced patients and the celiac disease patients, wanted commercial organizations to have the least influence on decision making, while the experts wanted them to have the most influence (I, II, III < IV). The mean scores for the desired influence of commercial organizations were between .6 and 1.0 point lower than those for the desired influence of independent researchers.

Finally, the groups differed significantly in their degree of trust in government (*F*(3, 1136) = 12.32, p <.001, ω = .17). The inexperienced public and the experienced patients trusted governments the least, while the celiac disease patients and the experts showed the most trust in government (I, II < III, IV). The groups differed significantly in their judgements about the level of influence of government (*F*(3, 1136) = 5.45, p <.001, ω = .11). Influence of governments was the least desired by experienced patients, followed by the inexperienced public, and the experts, and was appreciated the most by the celiac disease patients (II, I, IV < III) (see also Appendix 6).

*Perceptions and interest*

Table 6.8 shows the mean scores, the standard deviations and the differences between the four groups with regard to their perceptions of and interest in gene research.

**Table 6.8: Means, standard deviations, and differences between groups (ANOVA) for perceptions of and interest in gene research**

| | *General public samples* | | *Natural samples* | | | | |
|---|---|---|---|---|---|---|---|
| | **I – Inexperienced public (N=986)** | **II – Experienced patients (N=41)** | **III- Celiac disease patients (N=68)** | **IV- Experts (N=45)** | **ANOVA** | **Effect (ω)** | ***Post hoc tests (Hochbergs GT2)*** |
| | M (SD) | M (SD) | M (SD) | M (SD) | *F* (3, 1136) | | |
| *Perceptions of:* | | | | | | | |
| food issues | 3.31 (1.01) | 3.74 (1.02) | 3.83 (1.15) | 4.39 (.81) | 22.69*** | .23 | I< II, III< IV |
| medical issues[a] | 3.58 (.95) | 4.10 (.79) | 3.97 (.73) | 4.21 (.87) | 13.31*** | .18 | I< III, II, IV |
| *Interest in:* | | | | | | | |
| food issues | 3.57 (1.12) | 4.28 (.81) | 4.60 (.67) | 4.47 (.78) | 32.93*** | .28 | I< II, IV, III |
| medical issues | 3.25 (1.06) | 3.82 (1.02) | 4.30 (.84) | 4.13 (1.00) | 33.14*** | .18 | I< II, IV, III |

[a] When measurements of homogeneity of variance are broken, Welch F statistic and Games-Howell post hoc analysis are reported.
* p<.05, **p<.01, ***p<.001.

*Perception and interest* - Further analysis of the data showed significant differences between the four groups regarding their *perception of food issues* (*F* (3, 1136) = 22.69, p <.001, ω = .23) and *perception of medical issues* (*F*(3, 1136) = 13.31, p <.001, ω = .18), while significant differences were also revealed between the groups for *interest in food issues* (*F*(3, 1136) = 32.93, p <.001, ω = .28) and *interest in medical issues* (*F* (3, 1136) = 33.14, p <.001, ω = .18). Post hoc tests were used to follow up this finding. Perception of food issues was the lowest in the inexperienced public group, and significantly higher in the expert group with the two patient groups at an equal level ranking in between (I < II, III <IV). Perception of medical issues was significantly lower in the inexperienced public group, compared to the other groups (I < III, II, IV). Results showed that the interest in food issues was the lowest in the inexperienced public group. Differences between the celiac disease patients and the experienced patients or the experts were not significant (I <II, IV, III). The interest in medical issues was the lowest in the inexperienced public group and the highest in the celiac disease patient group, with smaller differences between the inexperienced public and either the experienced patients or the experts (I <II, IV, III) (see also Appendix 6).

In sum, the results indicated that, for all measurements, except for 'trust in friends and family', significant differences existed between the groups. The largest difference was found with respect to respondents' relative knowledge of gene research ($\omega$ = .42). Somewhat smaller, but still significant effects were shown for interest and perception of food issues ($\omega$ = .28 and $\omega$ = .23), information-seeking behaviour ($\omega$ = .24), need for information ($\omega$ = .20), respondents' level of general trust ($\omega$ = .20), and respondents' interest and perception of medical issues (both $\omega$ = .18). Small effects were shown for all other measures that differed significantly (ranging from $\omega$ = .08 till $\omega$ =.17).

### *6.3.4 Determinants of passive and active participation*

The third and final goal of this study was to examine which factors contributed to passive participation and which to active participation. First, a correlation analysis was conducted between the data from the inexperienced public (see Appendix 6). Passive participation was significantly correlated to all included prediction variables, except for 'trust in and desired influence of commercial organizations' and 'trust in and desired influence of governmental organizations'. All but these two variables were included in a hierarchical multiple regression analysis in order to predict passive participation. The results are shown in Table 6.9. The proposed model for passive participation explained 35% of the variance. These results suggested that the most determining factors of passive participation were respondents' relative knowledge of gene research and their information-seeking behaviour. The ascribed trust in and influence of friends and family contributed positively to passive participation, while the role of government negatively influences passive participation. Social involvement delivered a contribution to passive participation as well. Finally, the level of education negatively influenced passive participation.

The assessment of the factors that determine active participation was a more complicated matter. Earlier analysis had shown that only a very small percentage of the inexperienced public participates actively in gene research (see Table 6.4). Therefore, it was not possible to perform a reliable regression analysis with this sample. In addition, each of the three other samples – the experienced patients (N=41), the celiac disease patients (N=68) and the experts (N=45) – had too few cases to use regression analysis as well[10]. However, it was also known that respondents from both patient groups and the expert group were a more actively participating public. Thus, the three groups combined into a single sample (N=154). A correlation analysis was conducted within this 'convenient' sample (see Appendix 6). The analysis showed that active participation was positively

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[10] For regression analysis, at least 15 cases of data per predictor are recommended (Field, 2005).

correlated to the relative knowledge of gene research, the perception of food issues, information-seeking behaviour and to the trust in and desired influence of commercial organizations. Furthermore, active participation correlated negatively to the ascribed trust in and desired influence of NGOs. A regression analysis was performed which showed that the proposed model for active participation explains 44% of the variance (see Table 6.9). Again, the most important predictor was relative knowledge; it contributed positively to active participation, while gender had a negative effect, i.e., women were less inclined to active participation than men were. The influence of trust appeared to be not as great as had been expected.

**Table 6.9: Multiple regression analysis with passive participation and active participation as dependent variables (standardized)**

| | Inexperienced public (N=986) | | | | Patients and experts (N=154) | | | |
|---|---|---|---|---|---|---|---|---|
| | **Passive participation** | | | | **Active participation** | | | |
| Independent Construct | B | SE | ß | t-value[a] | B | SE | ß | t-value[a] |
| *Constant* | .29 | .14 | | **2.06** | 2.01 | .83 | | **2.41** |
| Age | .00 | .00 | .02 | .59 | -.01 | .01 | -.13 | -1.63 |
| Education | -.09 | .02 | -.12 | **-4.14** | -.21 | .13 | -.14 | -1.65 |
| Gender | -.02 | .03 | -.02 | -.07 | -.50 | .14 | -.28 | **-3.48** |
| | | | | | | | | |
| Social involvement | .09 | .02 | .15 | **5.22** | .01 | .09 | -.03 | -.41 |
| Citizen's participation | -.03 | .02 | -.05 | -1.63 | -.03 | .08 | .01 | .14 |
| | | | | | | | | |
| Interest in food issues | .04 | .02 | .10 | 1.80 | -.14 | .11 | -.12 | -1.30 |
| Interest in medical issues | .03 | .03 | .06 | 1.05 | .07 | .10 | .07 | .69 |
| Perception of food issues | -.03 | .02 | -.06 | -1.46 | .11 | .08 | .13 | 1.42 |
| Perception of medical issues | .02 | .02 | .03 | .72 | -.01 | .09 | -.01 | -.16 |
| | | | | | | | | |
| Information need | -.03 | .02 | -.04 | -1.21 | -.03 | .13 | -.02 | -.21 |
| Information-seeking behaviour | .13 | .02 | .24 | **7.25** | .15 | .10 | .13 | 1.54 |
| Relative knowledge | .31 | .03 | .29 | **10.42** | .51 | .15 | .29 | **3.47** |
| | | | | | | | | |
| General trust | .03 | .02 | .04 | 1.10 | -.05 | .11 | -.04 | -.43 |
| Trust and influence of commercial organizations | | | | | | | | |
| Trust and influence of friends and family | .06 | .02 | .09 | **3.13** | -.03 | .09 | -.03 | -.33 |
| Trust and influence of NGOs | -.04 | .02 | -.07 | -1.94 | -.18 | .09 | -.16 | -1.93 |
| Trust and influence of commercial researchers | -.01 | .02 | -.02 | -.73 | .15 | .10 | -.13 | 1.54 |
| Trust and influence of independent researchers | .03 | .02 | .06 | 1.57 | -.00 | .10 | -.00 | -.02 |
| Trust and influence of government | | | | | | | | |
| | $R^2$ = .34; | | | | $R^2$ = .44; | | | |
| | F = 29.60 (p< .001) | | | | F = 5.47 (p< .001) | | | |

[a] Based on two-tailed tests: for t-values > 1.96, p < .05; for t-values > 2.58, p < .01. Significant coefficients are in bold.

### 6.3.5 *Summary of the main results*

To sum up, the results indicated that the four publics – in their roles of inexperienced public, experienced patients, celiac disease patients and experts – participated in gene research to varying degrees. The inexperienced public was the least active; both patient groups participated more actively, whereas the expert group was the most actively participating in gene research.

*Differences in participation between the groups*
The findings showed that the groups differed significantly with respect to most measurements, while the specific patterns of these differences varied. The inexperienced public indicated to have the least *relative knowledge*, while experts considered themselves to be the most knowledgeable. Both patient samples ranked in between, at the same level. The inexperienced public *searched and required* less *information* than the other publics. No differences were found in the information-seeking behaviour of both patient groups on the one hand, and that of experts on the other, while the need for information was higher for celiac disease patients than for the other two active publics. For all groups, a significant difference was revealed between the reported need for information and their information-seeking behaviour, i.e., their need for information was higher than their information-seeking behaviour.

The inexperienced public and the experienced patients reported lower levels of general *trust* than the experts and the celiac disease patients did. Of the four groups, the experts trusted NGOs the least, while celiac disease patients trusted them the most. At the same time, both the inexperienced public and the experts favoured the same level of influence for NGOs, while the two patient groups differed the most with respect to this issue. Within all groups, general trust was high compared to trust in specific actors; only independent researchers were more trusted. In all groups, commercial organizations were the least trusted.

Furthermore, there was agreement between the four groups that commercial organizations should have the least influence on decision making. At the same time, for all groups, trust in independent researchers, and the desired influence on decision making for independent researchers scored the highest. For all groups, trust in commercial organizations, government, commercial researchers, friends and family, and even NGOs, as well as the desired degree of influence of these actors were lower than their overall level general level of trust.

Additionally, *interest in gene research* and *perception of gene research* were both lower for the inexperienced public than for the other, more active publics. The active publics did not differ in their interest in gene research, but they did in their perception of gene research. Between the four groups, experts perceived gene research the most positive.

Further comparison of the groups showed that the inexperienced public's mean levels for almost all measures were lower than the mean levels of experts. Both patient groups ranked in between, and their relationship with gene research varied in two ways: in some cases they shared the expert's opinion, whereas in other cases they agreed that of the inexperienced public. Additionally, the two patient groups differed from each other in their need for information and their level of general trust. Celiac disease patients reported higher levels for both constructs than did experienced patients. They also put significantly more trust in NGOs, independent researchers, and government than did the experienced patients. A similar pattern was observable for the influence on decision making of these organizations.

For most measures, the inexperienced public reported opinions that differed significantly from those of the experts. However, they had similar views about citizen's participation, their own social and political involvement in general, the desired level of influence in decision making of themselves, friends and family, and of NGOs. The two patient groups considered citizens' participation to be significantly more important than the other two groups. When no expertise knowledge was required – as is the case with social and political involvement and with the trust and desired influence ascribed to friends and family – the four groups did not differ.

*Predictors of passive and active participation*

Finally, the regression analyses revealed that predicting factors for passive participation were people's information-seeking behaviour and their relative level of knowledge about gene research. Furthermore, the level of education (negatively) and the level of social involvement predicted passive participation. The model explained 35% of the variance. Predicting factors for active participation were relative knowledge and gender. The proposed model explained 44% of the variance. Although expected, for both passive and active participation, no significant contributions were found for trust.

## 6.4 Conclusions from the survey

In this section, conclusions will be drawn based on the survey results. A general conclusion will be drawn and discussed in Chapter 7. The empirical research questions formulated in the beginning of this chapter are as follows:

*RQ3a: How do levels of participation in gene research (passive or active) differ between the selected samples?*

*RQ3b: How do these samples differ in their opinions about gene research, communication, and trust?*

*RQ3c: Which factors determine passive and active participation?*

*Levels of participation*

The findings show varying levels of participation in gene research, and it can be concluded that the inexperienced public is literally a passive public, while the other groups (experienced patients, celiac disease patients and experts) are more actively participating publics.

Between the four groups, experts represent the most active public. The two patient samples may also be viewed as active publics, while the inexperienced public plays the role of passive public.

*Public's relationship with gene research*

The four groups differ significantly between themselves with respect to most measurements from the survey, but patterns of these differences vary. Thus, passive and active publics differ in their relationship with gene research. The findings point to heterogeneous publics, where the same actors take different positions according to their specific role. For example, for all but three measurements (i.e., trust in NGOs, desired influence of NGOs and desired influence of government) lower mean levels are reported by the passive public than by the active publics (patients and experts). However, regarding aspects where no expertise knowledge was needed (social and political participation; trust, and desired influence ascribed to friends and family), all four publics do not differ. At the same time, active publics' opinions vary as well. This is most clearly shown in the role of patient. The relationship of patients (of both groups) with gene research varies in two ways: in some cases the patients agree with the expert (e.g., information-seeking behaviour), while in other instances the views of the inexperienced public were shared (e.g., trust in commercial organizations).

*Determinants of passive participation and active participation*

Finally, with respect to the analysis of factors influencing a passive or active role of a public, the results show that people's information-seeking behaviour, their relative knowledge of gene research, and their level of social involvement contribute significantly to a passive role, while their level of education contributes negatively to it. Contributing factors to an active role are relative knowledge and gender. Although expected, since its importance was shown previously in the results from focus group discussions, no significant contribution is found for trust.

Each of the empirical studies presented in this and the previous chapters (Chapters 4, 5 and 6) ended with conclusions about the study performed. This provided a better understanding of the relationship between publics and biotechnology or genomics. In the next chapter, the overall picture will be examined and the findings from the three studies will be related to the theoretical concepts and the two conceptual models analyzed in Chapter 2. The central question about the search for an improved understanding of the publics' relationship with science will be returned to.

## *Chapter 7*

# Conclusions and discussion
## Engaging the public?

*In this chapter general conclusions will be drawn with regard to the publics' relationship with science. Thereupon, these conclusions are discussed in more detail, limitations of the research project will be acknowledged, and implications and recommendations for future research and science communication practice are sketched.*

### 7.1 Introduction

In this research project, the publics' relationship with science is investigated. Central in this thesis is the question how this relationship can be understood from the perspective of the public. To recapitulate:

*RQ:* *How can the relationship between publics and science be understood?*

The theoretical understanding of this relationship is based on core concepts derived from two models in public understanding of science literature, the 'deficit model' and the 'interactive science model'. Based on a theoretical analysis of these core concepts (i.e., passive and active publics, information and communication, scientific knowledge, and trust), in a mixed methodology, the relationship between publics and biotechnology and genomics in particular was investigated empirically. To that end, based on the central question, three specific research questions were formulated as follows:

*RQ1:* *Which roles have publics played in Dutch biotechnology debates?*
*RQ2:* *Which considerations do publics in various roles have with respect to (communication aspects of) genomics?*
*RQ3:* *How do publics, passively or actively participating in gene research, differ in their relationship with genomics?*

In a document analysis the first research question was studied (Chapter 4). The second research question was investigated by means of focus group discussions (Chapter 5). And the third research question was the object of study in a survey (Chapter 6). In this chapter, general conclusions will be drawn about the relationship between publics and science, and the underlying theoretical concepts will be returned to (7.2). Subsequently, these conclusions will be discussed (7.3). The chapter continues with a reflection on the limitations of the research project (7.4) and finally, implications and recommendations for theory and practice will be given (7.5).

## 7.2 General conclusions

In this section the conclusions based upon the specific research questions will be recapitulated. Thereupon, the overall conclusions, the main research question and the core concepts derived from the two conceptual models in the literature on public understanding of science will be reviewed. As a reminder, these core concepts regard passive and active publics, scientific knowledge, information and communication, and trust.

### *Publics in the Dutch biotechnology debates*

In summary, conclusions from the first study, the document analysis (Chapter 4), are that the general public played various roles in the five Dutch biotechnology debates. Although an interested public was involved in the later debates, active participation was limited to a small number of people, who were not representative for the Dutch general public as a whole. The general public's influence on the political decision-making process about biotechnology has been rather insignificant. At best, the outcomes of the debates that were presented to parliament were taken into account as advice in its decision making. A mixture of both one-way communication and two-way communication processes was involved in the debates. One-way communication processes were aimed at informing the public, two-way communication processes mainly served the purpose of providing the public with opportunities for participation. Sometimes, these two-way communication processes were downplayed by the organizers of the debate. Finally, the conceptions of knowledge and trust changed during the debates. Initially, the debates were strictly aimed at the dissemination of scientific knowledge, in the belief that public trust would be gained by increasing people's knowledge. Later on, other types of knowledge and emotional arguments played increasingly important roles in the debates, while trust was now thought of as a much more complex concept. It became an important factor in the relationship between publics and science.

### *Publics' considerations about (communication aspects of) genomics*

Conclusions from the second study, the focus group discussions (Chapter 5), are that publics in their roles of inexperienced public, active consumers, patients, and experts all agree on the idea that interest in an issue such as gene research is related to one's personal involvement in the issue. People limit their interest, expressed in various ways, to a few issues. In all roles, publics agree that the communication process should entail more than mere dissemination of information, although the importance of knowledge is also acknowledged. Often, information in the complicated communication process is thought to be biased or, at least, specifically framed. Therefore, transparency and openness are considered important conditions in the communication process. Publics differ in their opinions about the way the communication process should be shaped. The inexperienced public wants information to be available, although people would not always actively search for it. In some cases publics would like to be actively involved in public debates. Active consumers emphasize the need to listen to the public, and patients empower themselves by taking a more active role in the communication process. In the more organized roles, publics are able to develop skills that enable them to engage actively in the broader policy and technology debate. Meanwhile, experts point to the need for knowledge about the issue and the necessity of educating the general public.

Within specific roles, publics vary in their opinions about influence on the decision making about gene research. The inexperienced public thinks that influence would be neither possible nor desirable. However, both active consumers and patients see themselves as more powerful and believe that they are able to exert a limited degree of influence. Experts are of the opinion that their own influence is (a minor) part of a broader, multifaceted decision-making process. In all roles, publics agree about industry being the most influential actor in gene research, which is why (increased) influence by other actors, such as NGOs, is desirable, as that might mitigate industry's position. In that context, publics also call for the creation of control mechanisms, such as controlled development and verifiability and transparency of research results.

Finally, in the relationship between publics and science, trust – or rather lack of trust - is an important theme which is emphasized by publics in all roles. (Communication) mechanisms to rebuild trust – such as openness about the sources and clarity about the senders' interests, transparency and solidarity – are mentioned as conditions that are required for rebuilding trust. Experts acknowledge the increasing lack of trust and point to their own diminishing levels of trust in industry. Furthermore, they see open and transparent communication, with opportunities for participation, as solutions to restoring trust.

### *Publics' participating behaviour in gene research*

From the third study, the survey (Chapter 6), it can be concluded that publics in their roles of inexperienced public, patients and experts, vary in their levels of participation in gene research. The inexperienced public does not participate in gene research and this public may be regarded as a *passive public*; experts are the most active participants in gene research and, hence, they can be considered an *active public.* Patients show intermediate participation levels. They, too, can be considered as active publics. Passive and active publics have different relationships with gene research. Passive publics report lower mean levels for most measurements (e.g., lower levels of interest in gene issues or lower levels of self-reported knowledge). However, for aspects where no expert knowledge is required, such as societal and political involvement, the publics do not differ from each other. Active publics do differ from each other in their relationship with gene research. For example, patients share experts' opinions about their information-seeking behaviour, while, at the same time, they identify themselves with the opinion of the inexperienced public where it concerns issues such as the trust they ascribe to, and the influence they desire for commercial researchers. Finally, it can be concluded that factors influencing a passive role of a public are their 'information-seeking behaviour', their 'relative knowledge of gene research', and their 'level of education (negative relation)' and 'social involvement'. 'Relative knowledge' and 'gender' contribute to an active role. Results did not confirm the expectations about the importance of trust.

*How to understand the relationship between publics and science?*

In general, the relationship between publics and science can be understood as a multifaceted relationship. First of all, it can be concluded that the inexperienced public is a *passive public,* which is not participating *en masse* in biotechnology, or in gene research. Publics, are only active – and then in small numbers – when the urge to be active is there. This *active public* plays for example the (unwanted) role of patients or, the role of active consumers, based on the notion of solidarity and shared responsibility.

Additionally, the conclusion can be drawn that scientists in their expert role are actively participating in science (in biotechnology or in gene research) mainly because of their expert position. For other issues it seems plausible to conclude that they behave the same way as publics in other roles do. The findings of the survey support this conclusion, as do the results of the focus group discussions, where experts describe their own participatory behaviour.

Thus, it can be concluded that within the general public various publics exist, each of which participate more or less actively in issues of interest. Publics in specific roles (e.g., patients, active consumers, experts) behave more actively than a more general and inexperienced public. These active publics want to be engaged, as has been proposed by the advocates of the interactive science model and these active publics want to be given the opportunity to empower themselves. However, the largest and inexperienced public is a passive public, which is neither knowledgeable about gene research nor particularly interested in it. This public can be considered as the inattentive public as defined by the deficit model.

Secondly, within the relationship between publics and science, *scientific knowledge* plays a role. Publics (both active and passive publics) consider knowledge as important, but only in particular situations, i.e., when needed for decisions and when interested in the issue. Experts think that people are able to make reasonable decisions, even with low levels of knowledge. Efforts aiming at providing a basic level of knowledge are therefore seen as less important, although they believe that information should still be available for people so that they may collect it if and when they so desire. Although in the debates at first it is thought that knowledge is neutral and that more knowledge will lead to increased support, as argued in the deficit model, this concept has evolved into an idea of 'embedded knowledge', where emotions may and should play a role and cannot easily be separated from facts, as supporters of the interactive science model argue.

Furthermore, the experts in the focus group discussions acknowledge that providing the public with more knowledge does not automatically lead to increased public interest. In addition, publics in all roles relate the concepts of knowledge and trust to each other. Therefore, it can be concluded that, in the relationship between publics and science, scientific knowledge functions as one among a number of different kinds of understanding within a social and political context.

Thirdly, in the relationship between publics and science, publics report a high need for *information and communication*, but this need is limited to one's own interests and relates to specific roles. In all roles, publics want information to be available for a variety of reasons: it is a democratic right for citizens to be informed, information may serve as an impetus for behavioural change, and it enables people to make deliberated choices. However, that need for information does not automatically lead to active information-seeking behaviour. The fact that people have varying levels of knowledge complicates attempts to dissemination of knowledge to the right places.

Experts acknowledge that information is important, but they also acknowledge that different people respond differently to information. Some need it, while others do not. For experts, informing the public and educating them through one-way processes are means to distribute information. Other experts emphasize two-way communication processes and argue that people are more knowledgeable than is often assumed. This mixing of both one-way communication (informing and persuading the public) and two-way communication (dialogue and mutual understanding) is also shown in the practice of the Dutch public debates on biotechnology.

In conclusion, both one-way processes of information and two-way processes of communication were used in the past and may again be used in the future in communication about science issues. Two-way processes, advocated by supporters of the interactive science model, are not always wanted by the general public, since they only actively participate in a few issues. One-way processes, proposed in the deficit model, are desired, but under conditions that prevent bias of information. Publics in all roles emphasize that information is biased and framed. Several mechanisms, such as openness, transparency, and the use of a variety of information sources, are suggested as ways to prevent this bias and to enable people to judge the information in a deliberated way. And although transparency and openness of information exist only to a certain degree, they consider these the prerequisite conditions for building on a trust relationship between publics and science.

Finally, in the relationship between publics and science, *trust* has become more central, as has been argued in the interactive science model. For publics, trust is a way to delegate their involvement in an issue. Trust that is placed upon organizations may diminish the need for public participation. Publics in all roles emphasize the importance of trust in the relationship between publics and science. Mechanisms that are required for (re)building public trust are transparency and openness of information, and the use of multiple sources of information. The results show that actors that are the most transparent and open, such as independent researchers (due to their peer review system) are trusted the most. However, trust cannot replace knowledge, but, rather, is complementary to knowledge. Conditionally related to trust is influence on the decision-making processes. In addition, the analyses show that commercial organizations are trusted the least, and that publics think that their influence ought to be the lowest as well. More influence is wanted when trust is diminishing, suggesting that, when actors have too much power, public trust in them will diminish.

In sum, the insights about the relationship between publics and science, gained in this research project, clearly show a multifaceted picture of this relationship from the perspective of the public. People play various roles, which are not clearly defined and, hence, people may switch from one role to the next. In their different roles publics may behave passively or actively. Furthermore, in the relationship between publics and science, aspects of scientific knowledge, information, communication, and trust play an important role. These are, however, not the only factors that influence the relationship between publics and science. The results show that the relationship is embedded in the political and social contexts as well.

## 7.3 Discussion

In this section, the theoretical contribution of this research project to the understanding of the relationship between publics and science will be discussed. The research project aimed at studying this relationship from the perspective of the public, contributing to the scientific understanding of the position of the core concepts within the two conceptual models and producing practical recommendations in order to encourage (science) communication about genomics. Suggestions for the latter will be made in the final section of this chapter. For now, the findings will be discussed in the light of the theoretical analysis of Chapter 2 and the methodological account presented in Chapter 3.

*Passive and active publics*

In the two ideal-typical conceptual models in public understanding of science, the conceptualizations of passive and active publics stand in stark contrast to each other (cf. Logan, 2001; J.D. Miller, 1992; Von Grote & Dierkes, 2000; Wynne, 1992, 1995). The findings in this thesis about active and passive publics are in accordance with two crucial observations in the literature, namely (1) that active citizens make up only a small part of the population (Leshner, 2005; Te Molder & Gutteling, 2002), and (2) that the largest part of the public is a passive public that can be considered inattentive (J.D. Miller, 1993; Wynne, 1995). Publics are active when there is an urge to be active. However, active participation by publics is limited to a few issues since, amongst other things, 'there is too much to know'. In the literature, this active attitude for a selected number of issues is known as 'issue specialization' of the public (Prewitt, 1982; Gaskell & Bauer, 2001, p. 63; De Loor et al., 1992). The findings from the present research project provide insight in the prerequisite conditions for participation, such as involvement in an issue. When publics are involved in an issue, they demand a more active and participatory role, which leads to their own empowerment. These findings confirm research by Grunig (1989), who found that the most active publics are most likely to communicate actively about issues, to be more knowledgeable about these issues, and to engage actively in participation activities.

In addition, the findings from the survey data about the differences in roles show that, within the general public, people fulfil various roles as Felt (2000) and Hill and Michael (1998) have argued. That people play various roles is supported by data from the focus group discussions. In both models, the public is considered not as a homogeneous, but rather as a heterogeneous public, whether it is segmented in an attentive public, interested public, or inattentive public, as J.D. Miller (1993) proposed, or whether it plays the role of an active public with its own expert knowledge, as has been argued by Wynne (1995).

*Scientific knowledge*

In the deficit model, scientific knowledge is identified as the key to resolving the problem of the general public's scientific illiteracy (Logan, 1999; J.D. Miller, 1995). It is based on the idea that increased knowledge will lead to higher levels of support for science (J.D. Miller, 1995; Trachtman, 1981). The findings from the analysis of the early Dutch biotechnology debates show that they were indeed based on the notion that more knowledge leads to a more positive perception of science (Hamstra, 1995). In the later debates, this belief about scientific knowledge was abandoned and scientific knowledge came to be seen as one among several kinds of knowledge, as advocates of the interactive science model argue (Silverstone, 1991; Wynne, 1991; Ziman, 1991). People's emotional arguments should be taken seriously as well, since people base their judgments not on scientific knowledge alone, as panel members explicated at the end of the debate on cloning. These panel members refer to 'sets of knowledges', as Sturgis and Allum (2004) have argued. The findings of this research project support the view that people do not base their decisions on scientific knowledge alone, as advocates of the deficit model believe, but instead they are made, based on knowledge derived from a variety of sources. Additionally, the results reveal that publics' decisions are also based on trust, as the experts in the focus group discussions point out (cf. the concept of socially robust science by Nowotny et al., 2001). Furthermore, the findings point to the use of knowledge in various ways. According to the experts in the focus group discussions, some people want to know everything before they will decide, while others base their decisions on a few bits of information. This supports the findings of Ziman (1991), who stated that the use of knowledge depends on the specific situation, and that knowledge is part of a complex and varied response.

In addition, the two opinions about the use of having scientific knowledge reported by experts also point to a variable response to knowledge. In the one opinion, having knowledge is important for a basic understanding. In the alternative view, having knowledge is less important, but, instead, knowledge should be available only when it is needed in a particular situation, i.e., it holds a less exclusive position (Ziman, 1991). Thus, clearly scientific knowledge is a more multidimensional concept than what it is given credit for by the proponents of the deficit model (Hansen, 2005).

With regard to levels of knowledge, the survey results confirm that the experts think they are the most knowledgeable about genomics. Other publics report less knowledge, but the active publics, in their role as patients, differ in this respect. Celiac disease patients regard themselves as more knowledgeable than the general patient group. The inexperienced public is clearly less knowledgeable, compared to both patients and experts. These findings confirm that having or wanting knowledge is restricted to issues that are either of importance to the public, or that the public is interested in (Gaskell & Bauer, 2001).

In sum, the findings about the role knowledge plays in the relationship between publics and science do not support a conceptualization of knowledge derived from the deficit model (Hansen, 2005). Instead, the ideas about knowledge derived from the interactive science model are consistent with those findings. This means that knowledge is embedded, is one among different kinds of understandings, is desired to be socially robust, and is related to other concepts such as trust (cf. Gibbons, 1999; Hansen, 2005; Nowotny et al, 2001; Silverstone, 1991; Wynne, 1991; Ziman, 1991).

*Information and communication*

The mixture of different types of communication processes shows that practice is different from theory, since, in the practice of the biotechnology debates, communication goals derived from *both* models are used. In part, this communication is communication transmission, as spelled out in the deficit model with the goal to persuade the public (Logan, 1999; Rowan, 1994); another part is aimed at dialogue and mutual understanding as proponents of the interactive science model have suggested (Rowan, 1994). However, as was the case in the public hearing in the GM debate, the two-way process was downplayed due to restrictions for the attending public imposed by the organizers. Informing was more emphasized instead of aiming at both informing and dialogue.

The analyses presented in this research project show that publics consider the concepts of information and - related to information - communication and knowledge important. There is a need for information – not only for the active publics, but for all publics – but this does not imply that active information-seeking behaviour by the public will follow. The results show that information and communication do not always involve a process of dialogue aimed at maximum participation or power in decision making, as the interactive science model assumes (Rowan, 1994).

In the interactive science model, the idea of transparent communication has not been worked out adequately. There is an emphasis on dialogue, and it is acknowledged that publics may be knowledgeable (Wynne, 1995), but open and transparent communication is automatically assumed. This has not been corroborated by the findings of the present research project, which, instead, point to biased information as one of the key issues in the processes of information and communication.

### *Trust*

The concept of trust receives more emphasis in the interactive science model than in the deficit model (Einsiedel, 2000; Logan, 1999; Von Grote & Dierkes, 2000). The results show that the notion of trust has changed, from a situation in the first debates, where trust is thought to be easily gained by increasing people's knowledge, to a situation in the later debates (cf. Luhmann, 1979; Neidhardt, 1993; Rowan, 1994; Slovic, 1993) where it is thought to be less one-dimensional and where it is found to be playing a key role in the publics' relationship with science. The data from the focus group discussions confirm this importance. In all roles, people agree with the key role of trust, as the interactive science model emphasizes (cf. Logan, 1999; Wynne, 1991).

In accordance with the theoretical assumptions, the data also reveal that the increasing lack of trust contributes to the difficult relationship between publics and science (Hansen, 2005). The belief that science and technology can be trusted is in decline (Hansen, 2005). The focus group data reveal that extensive memberships of participants in patient organizations, consumer organizations, and NGOs, are a signal that people place trust in these organizations. This type of social trust (Earle & Cvetkovich, 1995) is explained by Stzompka (1999) as a type of indirect reference to trust, possible by means of so-called 'pyramids of trust' (e.g., an expert is trusted because he works at a respectful university) and 'agencies of accountability' (e.g., agencies such as consumer organizations, to be trusted first, provide trustworthiness to other organizations such as governments). The survey data confirm the importance of these indirect references to trust. For example, trust in independent researchers and NGOs is the highest. However, while the focus group data point to the notion that trust in these organizations is also a way to delegate involvement; the survey data did not support this finding. In the latter data, the role of trust in passive or active participation was not confirmed.

There is trust in the scientific system or its representatives (Stzompka, 1999). Both the results from focus group discussions and the survey confirm this. The building of scientific knowledge depends on trust (Yearley, 2000). At the conceptual level, the concept of trust does not replace the concept of knowledge, but, instead, the concepts are interconnected as experts most explicitly stated when they argued that, when trust is lacking the need for knowledge is higher.

In accordance with findings from the literature that point to openness and public involvement as ways for rebuilding trust (cf. Slovic, 1993; Yearley, 2000), in the focus group data, mechanisms to build (or to rebuild) trust are mentioned. For example, transparency and openness of information (such as in peer review systems). However, whereas in the literature power sharing and public participation are to be aimed at (Slovic, 1993), the findings from the focus group discussions do not stress this as a final goal. Most of the inexperienced public participants indicate not to want much influence, although, when it concerns personal matters, they indicate that they do want influence. Additionally, some debate is wanted when products are developed. In other roles, such as those of active consumers and patients, people want to have influence, but this influence is limited to a few issues. A claim to public participation at the level of decision making is not made. The survey data support the idea that influence is not always wanted, as the largest part of the general public does not participate actively in gene research. However, findings from the document analysis reveal that opportunities for influencing decision making are not provided either, and thus the public cannot participate at this level. Therefore, trust will not be built (cf. Slovic, 1993).

To conclude, the main objective in this research project has been to gain more understanding of the relationship between publics and science. In general, taken together, the findings from the three studies give a multifaceted picture of this relationship (cf. Von Grote & Dierkes, 2000). Existing findings were confirmed (e.g., the importance of scientific knowledge and the role of information), and new understandings were added (e.g., the role of other knowledges, and the role of trust in this relationship). In sum, the following conclusions can be drawn.

First, concerning the relationship between publics and science itself, it can be concluded that publics fulfil various roles, and in these roles people may – either passively or actively or both – participate in gene research, or in other issues of science and technology. In active roles, publics want influence on and involvement in decision-making processes. In passive roles, such a claim to public participation is not made, but the need for open and transparent information and communication is still present. In all roles of the public, trust plays a leading part and scientific knowledge is considered to be only one of several sets of understandings that coexist simultaneously. To a large degree, roles determine in which activities people get involved, and to which extent, and which accompanying communication processes they look for in order to facilitate this involvement.

Secondly, from a theoretical point of view, the findings lead to the conclusion that the relationship between publics and science cannot be fully understood from either one of the two dominant perspectives suggested in the literature. Both perspectives appear to be too limited in their understanding of this relationship and, thus, need further elaboration. However, the analyses show that both models do make contributions to the understanding of this relationship. Similar concepts used in the two existing models are often variously defined in the two models. For example, with respect to the concept of information and communication, publics do not always want to be involved actively by means of two-way communication and participation mechanisms, but, nonetheless, they want information to be available when they require it. Rather than viewing the models as mutually exclusive alternatives, it is more fruitful to conceive them as complementary perspectives (cf. Einsiedel, 1999; Von Grote & Dierkes, 2000). Therefore, it can be concluded that – by starting at the conceptual level, and anchoring the empirical investigation of the publics' relationship with science in these concepts, rather than in either one of the two models – it was possible to contribute to more understanding of this relationship. The concepts included in the studies contribute to a better understanding of this relationship, since all three studies provide confirmation for (most) theoretical notions in the literature of the field, and, what is more, allow further specification of and elaboration on these concepts.

Thirdly, the use of mixed methodology also contributes to this improved understanding – more so than separate studies could have accomplished on their own – by laying bare the full complexity of the publics' relationship with science, which is much more all-encompassing than has been hitherto acknowledged (cf. Green at al., 2001). For example, part of the polemic between advocates of the two models is based on different emphases on the main concepts. In the deficit model, the main focus is on the lack of scientific knowledge and quantitative methods are most appropriate to address such a research interest. In the interactive science model, the active and participatory role of the public is the key concept, and this can be most fruitfully studied by employing qualitative methods. The findings from this thesis – from the analysis of the three studies combined – show that both conceptions do in fact complement each other. For example, the focus group discussions demonstrate that scientific knowledge contributes to people's understanding of science, but that it functions as only one among a number of understandings. Furthermore, the focus group discussions and the survey show that active publics would like to be engaged in gene research, but public participation is limited to only a few issues. Both the document analysis and the survey questionnaire show that the largest public is a passive public. The focus group discussions reveal the reasons behind these positions of publics.

Furthermore, the different methods of analysis make equally important contributions to this understanding, since the results from earlier methods served as input for subsequent ones (cf. Greene et al., 2001). Although integration occurred mainly in the analysis phase of the research, since data were collected separately, results from the first studies influenced the final design of the latter studies. Together with the general research question the studies had in common, these details of the design point to conditions that

Moran-Ellis et al. (2001) mentioned for an ‘integrated design’. In a ‘coordinated design’, mixing of methods only takes place at the level of analysis (Green et al., 2001; Moran-Ellis et al., 2001).

Finally, a review of the literature in the field of public understanding of science shows that, in the past, results from separate studies tended to be judged against the methodological paradigm favoured by the researchers in question (cf. Sturgis & Allum, 2004; Wynne, 1995). Both by choosing to ground the empirical studies in theoretical concepts instead of in (one of the two prevailing) models, and by employing a mixed methodology, it is possible to circumvent this controversy.

### 7.4 Limitations of the research project

Some limitations of the research project should be acknowledged. First, some methodological considerations will be discussed. In the research presented in this thesis, mixed methodology has been used to facilitate the integration of the three perspectives from the separate empirical studies into a single, coherent framework of understandings about the relationship between the public and science. Although the design was aimed at an ‘integrated design’, where integration between methods took place from the point of conceptualization onwards and across all stages of the research, integration took place not in its pure form, due to factors such as the restrictions of time and money. A different mixed methodology design, with more opportunities for integration from the stage of design onwards, could have led to a greater level of integration of the findings.

Second, some considerations about the possible inferences have to be addressed as well. The empirical studies investigated the publics’ relationship with biotechnology and genomics, while concepts were derived from conceptual models that concerned public understanding of science in general. Caution is called for when using inferences from applied issues such as biotechnology and genomics to science in general, since it is known, for example from survey studies (cf. Gaskell & Bauer, 2005), that publics respond differently to various science issues.

Another limitation concerns the fact that although attempts have been made to incorporate a large amount of literature about the concepts studied in this thesis, from various areas (e.g., risk communication, health communication and public participation), this coverage has not been exhaustive. Therefore, the theoretical conceptualizations used are limited in themselves and caution is in order when inferences are drawn from them. Yet, the conceptualizations, complemented by the findings from the empirical studies, sketch a useful picture of the theoretical contours of the relationship between publics and science, which lays a solid foundation for further research in this field of study.

## 7.5 Implications and recommendations

(A better) scientific understanding of the relationship between publics and science is a prerequisite for designing communication strategies for science and technology in general, as well as for designing communication strategies for biotechnology and genomics in particular. Despite the fact that the current research project could only raise a corner of the veil, some suggestions can be formulated for future research as well as for future communication strategies.

*Future research*

In order to understand more of the relationship between publics and science, the findings show that concepts derived from to the deficit model and the interactive science model require refinement. Both models contribute to understanding of this relationship, but they also have their limitations. Therefore, future research aimed at refinement of the theoretical framework – which might ultimately lead to an 'integrated' model of science communication – should be encouraged. Such research should pay special attention to a number of critical issues.

More attention should be directed towards to the roles people play. Publics' involvement in a given issue is in part determined by their experiences, and these have repercussions for the dynamics of these roles. Thus, these roles, and the way roles change – e.g., the moments of transition from one role to another – affect publics' levels of participation and their need for information and communication. In other words, further research should focus on publics' roles and the way these roles change, as well as on the implications of these changing roles for the design of communication processes in practice, i.e., the way information and communication should, ideally, be offered and which effects communication processes might accomplish.

Apart from the implications that the (changing) roles publics play, have for the design of science communication processes, there are three other themes that warrant future research. Firstly, it is of interest to study the question when, why and how publics participate in science issues, since answers to these questions may lead to further insight about specific roles publics play. Not only active publics require further study, but the larger passive public, too, deserves more attention. For example, from the perspective of policymakers, it is of interest to study how publics could be encouraged to engage in science. At the moment, public participation and citizenship has mainly been studied from health, environmental or political perspectives, and not often from the perspective of science communication. Future research may profit from the findings from other fields, such as those in health communication, where it became clear that the processes of coaching, encouraging and teaching people how to participate may lead to higher levels of participation and to increased empowerment of the public.

Secondly, since people have indicated that transparent and open information and communication are important for them, the popularization of scientific knowledge – be it disseminating scientific information or communication via two-way processes – is a theme of interest. The point of departure for research on this issue could other findings that investigated dissemination of science and technology, or research from risk communication and health communication focusing on two-way communication.

Thirdly, under the surface of open and transparent information and communication trust always plays a role. Therefore, the role of trust in the communication about science and technology issues – and especially in biotechnology and genomics – may provide another avenue for future research.

Fortunately, this year the University of Twente starts with a new, accredited Masters Program in Science Education and Communication, which will include both teaching and research activities. Research plans are in the making that will contribute to this new Masters Program, which will focus on communication strategies with regard to new technologies, and the role of public participation and citizenship in the relationship between publics and science. The present thesis is a first step in the realization of these plans.

### *Future communication strategies*

Science communication in theory is something altogether different from science communication in practice. At this point some recommendations will be made, especially for researchers and policymakers who show concern about the relationship between publics and science. From the findings it becomes clear that the specific nature of the roles publics play and the moments when these roles change determine which kind of communication publics require. In some roles, publics want information to be available, while, in others, publics want to get involved in decision-making processes. Although, currently, only a small percentage of the public is actively involved in science issues, this does not mean that there is not room for expansion of opportunities for active public engagement. The composition of a given public will change continuously and, therefore, there will always be a (small) public that wants participation, and a pro-active role of policymakers and researchers is to be recommended.

With regard to information, the key issues are openness and transparency, as these are ways to build trust. Since researchers are still the most trusted actors, a special role is assigned to them. They should, in their role as experts, contribute to an open and transparent process of communication. Due to their independent position, they may serve as ‘trustworthy’ sources of information. Hence, when it comes to science and technology – and especially biotechnology and genomics – researchers themselves should be encouraged to play a more active role in the science communication about science and technology in general and about biotechnology and genomics in particular. This call for an active role for the researcher echoes the call for ‘scientific citizenship’ by Davies and Wolf-Philips (2006), when they argue in favour of scientists playing a broader role than that of mere experts and contributing to building bridges between science and society.

Furthermore, this communication does not always have to be a two-way process. Seen from the interactive science perspective, one-way communication means are considered undesirable, since these do not actively involve the general public. However, the findings from this research project show that – although not everyone wants to be engaged, or is interested in an issue such as genomics – publics do want information to be available. This can be provided also, but not exclusively, through one-way communication processes. Other publics want more, and feel the need to participate or even to get involved in decision-making processes about issues of importance. They want to be engaged in particular issues. Mechanisms for two-way communication may contribute to these processes of involvement, and researchers may contribute to this engagement by coaching or encouraging publics. In sum, considering which communication or participation mechanisms to use is best done on a case-by-case basis. This means that all communication goals – such as self-expression, listening, informing, entertaining, negotiating and persuading – should be possible and strived after (cf. Rowan, 1994). Meanwhile, participation mechanisms should also be considered.

A final recommendation concerns policymakers. Inspired by a democratic rationale, they would like the public to participate in science and technology issues. A small part of the population desires this, but most others do not long for an active role. However, information should be available, as well as opportunities to participate. The aim should not be to persuade people but rather to support them, so that they may empower themselves when the moment is there and engage themselves in science and technology in general, or in biotechnology and genomics in particular. Denying them these opportunities would imply that when publics change roles – and this happens all the time – and desire more involvement, but information is not available or participation is not possible, crisis situations will be created, which require extra attention and money. These situations may be avoided by an open and pro-active attitude of both policymakers and researchers.

Finally, based on the insights gained in this research project, as well as considering the limitations, with the current research project a contribution has been made to a better understanding of the relationship between the public and science by adding more scientific understanding to the key concepts involved in this relationship, by formulating recommendations for future research, and by providing practical recommendations for science communication strategies. In sum, this research project provides a useful contribution to the existing literature about publics' understanding of science. Its findings confirm existing findings, while also opening up new areas of research, and contributing to the improvement of science communication in practice.

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# *Appendices*

*Appendix 1 References to documents used in the analysis*
*Appendix 2 Protocol focus group discussions (in Dutch)*
*Appendix 3 Interviewed genomics experts*
*Appendix 4 Text of the examples in focus group discussions (in Dutch)*
*Appendix 5 Survey questionnaire (in Dutch)*
*Appendix 6 Figures with mean scores and correlation matrices*

# Appendix 1

# References to documents used in the analysis

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# *Appendix 2*
# Protocol focus group discussions (in Dutch)

**Opzet Protocol focusgroepen publiek en genomics**
Totale duur sessie: 2 uur

- **Richtingen met mogelijke voorbeelden**

**GROEP A: Diagnostiek en geneesmiddelen**

Voorbeelden:

1. Medicijnen op maat
2. Pre Implantatie Diagnostiek en navelstrengbloed
3. Betaalbare medicijnen

**GROEP B: Gemengd**

Voorbeelden:

1. Allergievrije appel
2. Medicijnen op maat / evt. noemen DNA afslankpil
3. Pre Implantatie Diagnostiek en navelstrengbloed

**GROEP C: Gezonde voeding**.

Voorbeelden:

1. Broccoli en kanker
2. Allergievrije appel
3. DNA afslankpil

**Overzicht:**

A Algemene introductie (10 minuten)
B Eigen visie en invloed op genenonderzoek/ genetisch onderzoek adhv voorbeelden (30 minuten)
  Eigen rol en invloed (10 minuten)
  Visie en opinie van anderen (20 minuten)
  Rol en invloed van anderen (20 minuten)
  Rol communicatie (10 minuten)
  Rol vertrouwen (10 minuten)
C Conclusies en afsluiting (5-10 minuten)

**A0 Ontvangst**
**A Algemene introductie 10 - 15 minuten**

- Welkom
- [Bedanken voor aanwezigheid en het invullen van de korte vragenlijst].
- Introductie van de moderator en observator: Mijn naam is X en ik ben vandaag de gespreksleider van de discussie die we zo gaan voeren. Aan de tafel daar zit Anne Dijkstra. Zij is de onderzoeker bij dit project en zal aantekeningen maken en er opletten dat de

opnameapparatuur werkt. Deze discussie is samen met andere discussies deel van een groter wetenschappelijk onderzoek naar publiek en wat verschillende groepen vinden van het genenonderzoek (genomics). Het onderzoek wordt gefinancierd door geld van het ministerie van OC&W (NWO) en vindt plaats bij de Universiteit Twente. Het onderzoek is geen marketing onderzoek.

- De gesprekken worden opgenomen op video & er vindt voor de zekerheid een geluidsopname plaats. De opnames worden alleen gebruikt door de onderzoeker, respondenten blijven altijd anoniem.
- Doel van het onderzoek: "Een idee krijgen wat men vindt van het genenonderzoek en toepassingen daarvan en een idee krijgen wie welke rol en invloed zou mogen of moeten uitoefenen bij het doen van onderzoek en het toelaten van toepassingen."

Voor de groepen met experts/betrokkenen: Een belangrijk doel van het onderzoek is om na te gaan op welke punten uw analyses en argumentaties verschillen van de analyses en argumentaties van leken. We leggen aan u voor een belangrijk deel dezelfde kwesties en vragen voor als aan enkele groepen waarin leken deelnemen. Het kan dus zijn dat een aantal van de zaken die we de revue laten passeren door u als expert/direct betrokkenen worden ervaren als 'open deuren'.

- De discussie gaat komende twee uur over het genenonderzoek (nieuwe term: genomics), de visie van jullie hierop, de argumenten waarmee jullie je visie onderbouwen en de vraag wie welke rol in de discussie hierover heeft of zou moeten hebben.
- Aan het eind is er nog tijd om aanvullende vragen te stellen over dít onderzoek (niet over genomics onderzoek iha). Die zullen dan door Anne Dijkstra worden beantwoord.
- Ik wil benadrukken dat u vrij bent om uw mening te geven. Dat is zelfs belangrijk voor het onderzoek. Ook zijn er geen goede of foute antwoorden. [Het geeft niets als men een keer iets niet begrijpt. Laat dat ook weten.] Soms zal ik omwille van de tijd genoodzaakt zijn de discussie af te breken, want we hebben veel onderwerpen te bespreken. Wel graag elkaar uit laten spreken (ook ivm analyse van de gesprekken).
- Dan wil ik nu graag beginnen met de vraag of u zich kort wil voorstellen met het noemen van uw naam, leeftijd, (gezinssituatie), werkzaamheden en uw eventuele betrokkenheid met het genenonderzoek.

***[15 minuten]***

**B Visie op genenonderzoek / genetisch onderzoek adhv voorbeeld(en) met daarbij eigen rol en invloed**

Groep A: Diagnostiek en geneesmiddelen
Groep B: Gemengd
Groep C: Gezonde voeding

- ***[3 voorbeelden per richting]***
- *Sheet laten zien en geven met* ***voorbeeld***

**B1 Eigen visie/opinie 3 x 10 minuten**

- Rondje: Welk algemeen beeld heeft u van genenonderzoek?

- Daarna voorbeeld laten zien.
- In hoeverre bent u bekend met voorbeeld?
- Hoe staat u hier tegenover? Wat denkt u erbij, wat voor gevoel heeft u erbij? Waarom? Positief/ negatief
- Hoe reëel denkt u dat de toepassing geschetst in het voorbeeld is? Waarom?
  ***Bovenstaande vragen meerdere keren met andere voorbeelden doorlopen.***
- U heeft naar aanleiding van de voorbeelden een aantal dilemma's genoemd. Kent u andere voorbeelden (die dergelijke dilemma's oproepen)?

***[45 minuten]***

**B2 Eigen rol en invloed 15 minuten**

- Wat voor invloed heeft u (als burger, of als organisatie) op het genenonderzoek?
- Wat voor invloed zou u zelf (als burger, of als organisatie) willen hebben bij het genenonderzoek? Waarom?
- Kunt u (als partij) ontwikkelingen stimuleren of tegenhouden? Kan Nederland dat alleen beslissen?

***[60 minuten]***

**B3 Informatiebehoefte 10 minuten**

- Is het belangrijk dan ook kennis over het onderwerp te hebben?
  Waarom / waarom niet?
  Heeft u ook deze kennis?
- Wilt u in het algemeen weten wat er gebeurt en hoe het werkt op genen-onderzoekgebied? Waarom?
- Hoe belangrijk is het dat u veranderingen/ ontwikkelingen begrijpt? Waarom of waarom niet?
- Wie spelen er een rol bij het informeren over en vormen van een opinie over genenonderzoek? Welke rol?
  - experts/ wetenschappers
  - bedrijfsleven/ industrie
  - overheid/ politici
  - journalisten/ media
  - maatschappelijke organisaties
  - algemeen publiek

***[70 minuten]***

**B4 Opinie en rol van anderen 20 minuten**

- Welke andere partijen spelen volgens u een rol in het genenonderzoek in het algemeen/ de besproken voorbeelden?
  - experts/ wetenschappers
  - bedrijfsleven/ industrie
  - overheid/ politici
  - journalisten/ media
  - maatschappelijke organisaties
  - algemeen publiek

- Hoe ziet u de rol van de verschillende betrokken partijen bij genenonderzoek, welke rol spelen ze en welke rol moeten ze spelen?
- Welke rol spelen de media bij het informeren over en vormen van een opinie over genenonderzoek?
- Wat voor invloed hebben verschillende partijen op het genenonderzoek?
  - experts/ wetenschappers
  - bedrijfsleven/ industrie
  - overheid/ politici
  - journalisten/ media
  - maatschappelijke organisaties
  - algemeen publiek
- Wat voor invloed zouden de verschillende partijen moeten hebben op het genenonderzoek? Waarom?
- Zou het algemene publiek een rol hierbij moeten spelen en invloed op het genenonderzoek moeten of mogen hebben?
  - [Of: Hebt u het idee dat (u als) algemeen publiek zelf een rol speelt bij het ontwikkelen van nieuwe technologieën als genomics.]
  - Waarom wel of waarom niet?
  - Op welke manier zou het algemeen publiek invloed moeten kunnen uitoefenen?
    - Participatie? Andere manieren?
  - Hoe ver zou deze invloed kunnen gaan?
- Als partijen invloed uitoefenen op het beslissingsproces over het genenonderzoek. Hoe belangrijk is het dat de partijen kennis over het genenonderzoek hebben? Waarom?
  - experts/ wetenschappers
  - bedrijfsleven/ industrie
  - overheid/ politici
  - journalisten/ media
  - maatschappelijke organisaties
  - algemeen publiek
- Welke kennis zou elk van de partijen moeten hebben? Waarom?

- Waar halen zij hun informatie vandaan? ***Alleen voor experts***

- Denkt u dat deze partijen ook deze kennis hebben?

***[90 minuten]***

### B5 Rol communicatie 10 minuten

*Genenonderzoek is niet los te zien van maatschappelijke ontwikkelingen. Daarom wordt op verschillende manieren gecommuniceerd over dit onderwerp met of naar het algemeen publiek. Die informatie-uitwisseling kan verschillende vormen aannemen. Op die communicatievormen willen we nu iets dieper ingaan.*

- Hoe wordt door verschillende partijen gecommuniceerd over het genenonderzoek?
- Wat vindt u van deze communicatie?
- Hoe zou de communicatie door verschillende partijen eruit moeten zien? Waarom?
  - experts/ wetenschappers

    - bedrijfsleven/ industrie
    - overheid/ politici
    - journalisten/ media
    - maatschappelijke organisaties
    - algemeen publiek

***[100 minuten]***

**B6 Rol vertrouwen 10 minuten**

*Vertrouwen wordt altijd genoemd als een belangrijk aspect bij de beslissingen over genenonderzoek. [Dit is ook in dit gesprek van vandaag al genoemd]*

- Hoe proberen partijen het vertrouwen van het publiek te krijgen en te houden?
- Wat vindt u daarvan? Waarom?
- Hoe zouden partijen het vertrouwen moeten winnen? Waarom?
- Voor het algemeen publiek: Hoeveel vertrouwen heeft u in de genoemde partijen?

NB: ook nog rol van onzekerheid?

- We hebben nu zaken besproken als vertrouwen, de rol van kennis, de invloed en rol van verschillende partijen. Welke factoren spelen volgens u nog meer een rol bij het communicatieproces rond het genenonderzoek.
    - Op ingaan?
    - Waarom een belangrijke factor? Visie?

***[110 minuten]***

**B7 Eventueel ter afsluiting**

- Hebt u al eens informatie opgezocht over genenonderzoek / over voorbeelden?
  Hoe dan en waar en wat hebt u gevonden?
  Hoe nuttig en bruikbaar was deze informatie?
  Wat wilt u nog meer weten?
  Waarom?
        - Rol soorten kennis
        - Welke bronnen

**C Conclusies en afsluiting 5 minuten**

- Zijn er nog punten of zaken die we vergeten zijn? Heeft u nog andere punten? Wilt u nog vragen stellen?
- Zijn er nog vragen over het onderzoek, altijd kan contact worden opgenomen met Anne Dijkstra, e-mail: a.m.dijkstra@utwente.nl of via telefoonnummer 053 4893316.
- Wijzen op vergoeding en invullen van formulier met enkele vragen over demografie en achtergrond
- Bedanken en afsluiten.

# *Appendix 3*
# Interviewed genomics experts

| Type organization | Name, organization |
|---|---|
| NGOs | Huib de Vriend<br>LIS Consult, Dutch Consumer & Biotechnology Association |
| | Frits Janssen<br>Dutch Celiac Disease Association, patient association |
| Network organization | Frans van Dam<br>Centre for Society and Genomics, communication officer |
| | Gijs van der Starre<br>Netherlands Genomics Initiative, NWO |
| | Rob Janssen<br>Director NIABA, umbrella organisation biotechnology companies |
| Sciences | Prof. dr. Theo Verrips<br>University of Utrecht, cellular biologist, chair IOP Genomics, Unilever |
| Social sciences | Prof. dr. Cees van Woerkum<br>Wageningen University, Communication and Innovation Sciences |
| Philosophy, ethics | Prof. dr. Michiel Korthals<br>Wageningen University, Societal aspects of Genomics research, philosopher, ethicist |
| Government, politics | Henk Jan Ormel<br>Member House of Lords for Christen Democrats |
| | Dr. Benno ter Kuile<br>Senior Policy Advisor Office for Risk Assessment, Dutch Food and Safety Authority |
| | Prof. dr. Rietje van Dam |
| | COGEM (chairwoman Subcommission Ethics and Societal Aspects) |
| Industry | Willem van Weeperen<br>Genzyme, director section Netherlands, pharmaceutical industry, e.g. Pompe disease |
| | Harry Jasken<br>Avebe, potato industry, director communication |
| Science journalism | Maarten Evenblij<br>Free lance journalist, e.g., for De Volkskrant |

# *Appendix 4*
# Text of the examples used in the focus group discussions

## Medical examples

### *Gene identification*

**Medicijnen op maat?**

Mensen kunnen heel verschillend reageren op medicijnen. Niet ieder medicijn is bij alle patiënten even effectief. Waar de een hoge dosering nodig heeft, volstaat bij een ander een lage dosering. Dat maakt het voor artsen altijd lastig om na het stellen van een diagnose het juiste medicijn in de juiste dosering voor te schrijven.

De laatste jaren komt men steeds meer te weten over de genetische achtergronden van de gevoeligheid van mensen voor medicijnen. Dit wordt ook wel aangeduid met de engelse term ‘pharmacogenetics’. Uiteindelijk hoopt men zo ver te komen, dat er van iedere patiënt een soort ‘genetische kaart’ kan worden gemaakt waaruit duidelijk wordt hoe gevoelig men is voor bepaalde medicijnen. Op basis van zo’n ‘genetische kaart’ zou men dan per individu medicijnen op maat voor kunnen schrijven, die naar soort en dosering het meest effectief zijn. Dan kan ook worden voorkomen dat sommige patiënten onnodig medicijnen of doseringen krijgen voorgeschreven die vervelende bijwerkingen hebben, bijvoorbeeld bij het ondergaan van een chemokuur voor de behandeling van tumoren/kanker.

Deze ‘medicijnen op maat’ werkwijze heeft wel enkele consequenties, zoals:
Patiënten moeten zich genetisch laten onderzoeken. Daarbij kan meer informatie boven water komen dan alleen de informatie die relevant is voor de ziekte die hij/zij heeft;
Artsen moeten de vaak complexe informatie goed kunnen beoordelen.

### *Pre Implantation Diagnostics*

**Preïmplantatie genetische diagnostiek en screening**

Als in hun familie een ernstige erfelijke aandoening voorkomt, zoals de ziekte van Huntington1, dan kunnen mensen met een kinderwens er al langere tijd voor kiezen vroeg in een zwangerschap de foetus te laten onderzoeken.

Een recentere optie is: in-vitrofertilisatie (IVF, ook wel bekend als ‘reageerbuisbevruchting’) in combinatie met genetisch onderzoek voorafgaand aan de implantatie. Embryo’s met een erfelijke afwijking worden dan niet in de baarmoeder geplaatst. Een voordeel is dat de eventuele keuze voor een abortus zo wordt vermeden. Nadeel is dat IVF belastend is (o.a. vanwege hormoonbehandelingen) en niet altijd tot zwangerschap leidt.

Ten tweede kunnen embryo’s geselecteerd worden op hun geschiktheid om na de geboorte via cellen uit het navelstrengbloed een broer of zus met een levensbedreigende ziekte te helpen. Een ouderpaar met een ziek kind kan er dan voor kiezen om een broertje of zusje geboren te laten worden dat geschikt is om te dienen als donor van navelstrengbloed (wat voor het pasgeboren kind verder niet schadelijk is). Om een embryo dat over de geschikte erfelijke kenmerken beschikt te kunnen selecteren moet dat dan wel door middel van IVF in combinatie met genetische selectie worden geconcipieerd.

In Groot-Brittannië hebben de ouders van een kind met een ernstige, erfelijk bepaalde vorm van bloedarmoede in 2001 verzocht om via deze weg een broer/zusje geboren te laten worden dat én de ziekte niet had en geschikt zou zijn om als beenmergdonor voor het zieke broertje te dienen. Ondertussen zijn meerdere aanvragen voor "baby's op maat" geweest, maar er is er nog geen geboren.

*Eventueel voor ná de discussie*
Volgens de Gezondheidsraad is selectie hierop alleen verantwoord als het kind zelf welkom is. Zorgvuldige counseling is een voorwaarde.

*1 Uitleg over de ziekte van Huntington:*
De ziekte van Huntington is een erfelijke aandoening als gevolg van een afwijkend gen die bepaalde delen van de hersenen aantast. De eerste symptomen openbaren zich meestal tussen het 35ste en 45ste levensjaar, maar kunnen ook eerder of later in het leven optreden. Zij uit zich o.a. in onwillekeurige bewegingen die langzaam verergeren, verstandelijke achteruitgang en een verscheidenheid aan psychische symptomen. De ziekte leidt gemiddeld na een achttiental jaren tot de dood van de patiënt, meestal door bijkomende oorzaken zoals longontsteking. De jeugdvorm begint doorgaans in de tienerjaren. Deze vorm kenmerkt zich, in plaats van door onwillekeurige bewegingen, vooral door spierstijfheid. Er is geen behandelmethode. In Nederland lijden circa 1300 mensen aan de ziekte van Huntington. Naar schatting zijn er daarnaast circa 4000 mensen die risico lopen op de ziekte.
Indien één van de ouders het afwijkende (Huntington) gen heeft, dan heeft elke zoon of dochter 50% kans de ziekte te erven. Bij diegenen, die het Huntington-gen hebben geërfd, zal de ziekte zich openbaren als zij lang genoeg leven. Als het gendefect met een diagnostische test kan worden aangetoond weet je met 100% zekerheid dat je de ziekte krijgt.

## *Affordable drugs*

**Betaalbare medicijnen**
Met de kennis van genetica worden er nieuwe medicijnen voor kankerpatiënten ontwikkeld, die heel gericht de ontwikkeling van tumoren kunnen remmen. De kosten om zulke medicijnen te ontwikkelen zijn erg hoog, en de medicijnen zijn erg duur.
Het biotechnologiebedrijf Genentech en het farmaciebedrijf Hoffmann- La Roche hebben samen een nieuw medicijn tegen kanker ontwikkeld: Avastin. De werking van het medicijn is gebaseerd op een humaan antilichaam voor VEGF. VEGF staat voor 'Vascular Endothelial Growth Factor'. VEGF speelt een belangrijke rol bij de vorming van nieuwe, kleine bloedvaatjes, en speelt daarmee een belangrijke rol bij het herstel van beschadigd weefsel (wonden).
Tumoren kunnen groeien dankzij de toevoer van bloed via kleine bloedvaatjes. Als je die groei van

bloedvaatjes in de omgeving van een tumor kunt remmen, dan kun je ook de groei van de tumor remmen. En dat is precies wat het antilichaam in Avastin doet: het blokkeert de werking van VEGF, en blokkeert daarmee de vorming van nieuwe bloedvaatjes. De bloedtoevoer wordt afgesloten en de tumor kan niet verder groeien.

Avastin wordt gemaakt met recombinant DNA-technieken, ofwel genetische manipulatie. Die techniek maakt het mogelijk om op grote schaal humane antilichamen te maken.

Avastin kan worden toegepast voor de behandeling van diverse vormen van kanker.

De kosten van behandeling zijn echter erg hoog. De behandeling van een darmkankerpatiënt met Avastin kost per jaar ongeveer 50.000 dollar, de behandeling van een borstkankerpatiënt is zelfs twee keer zo duur.

De omzet van Avastin bedraagt op dit moment ongeveer 1 miljard dollar per jaar. Genentech en Hoffmann-La Roche verwachten in 2009 de omzet te hebben verzevenvoudigd.

## Food examples

*Broccoli and lung cancer*

**Broccoli en longkanker**

Nieuw onderzoek heeft opnieuw het beschermende effect van broccoli tegen kanker aangetoond. Al langer is bekend dat broccoli veel antioxidanten bevat. Dit zijn vitamines en mineralen die een preventief beschermende werking hebben. In het lichaam zijn schadelijke stoffen actief, de vrije radicalen. Die tasten essentiële onderdelen van lichaamscellen aan, zoals het DNA (het erfelijk materiaal). Stoffen die als antioxidant werken, kunnen deze radicalen onschadelijk maken. De bekendste antioxidanten zijn de vitamines A, C en E en de mineralen zink en selenium, waar broccoli vol van zit. Het nieuwste onderzoek wijst uit dat broccoli, spruiten en andere koolsoorten ook hoge concentraties zogeheten isothiocyanaten bevatten. Ook dat zijn stoffen die bescherming bieden tegen longkanker.

Nadeel is alleen dat de preventieve werking van deze stoffen alleen bij mensen optreedt die niet of in mindere mate over de genen GSTM1 en GSTT1 beschikken. Deze genen produceren namelijk een enzym dat die isothiocyanaten afbreekt. Als de mensen met het juiste genenpakket ten minste drie maal per week kool eten, lopen 33 tot 37 procent minder risico op kanker. Als beide genen niet of op slechts beperkt functioneren, hebben mensen 72 procent minder kans op kanker, volgens de onderzoekers. Voor een optimaal gezonde samenstelling van je voedingspakket lijkt het dus zinvol om na te laten gaan over welk genenpakket je beschikt.

*Extra informatie voor ná de discussie*

(Volgens het Koninging Wilhelmina Fonds Kankerbestrijding, en vele andere organisaties en deskundigen, is de rol van voeding bij het ontstaan van kanker echter bescheiden. Niettemin is een regelmatig terugkerende portie broccoli of andere koolsoort een must voor een gezond leven.)

*Allergy free apple*

**Wagenings onderzoek brengt allergeenvrije appel binnen handbereik**

Ongeveer 2% van de West-Europese bevolking leidt aan appelallergie. Door erfelijke gegevens te combineren met de resultaten van huidpriktesten bij allergische patiënten is meer inzicht ontstaan in de betrokkenheid van specifieke genen bij deze vorm van allergie.

Eerder is aangetoond dat appelallergie wordt veroorzaakt door één of meerdere eiwitten in appel (zogenaamde Mal d1 t/m Mal d4-eiwitten). Mal d1 is het belangrijkste allergeen in appel. Personen die allergisch zijn voor het Mal d1 eiwit hebben na het eten van een verse appel last van jeuk, tintelingen en zwellingen van lippen, tong en keel.
Uit het Wagenings onderzoek blijkt dat meerdere allergenen samen een rol kunnen spelen en dat patiënten onderling verschillen in hun gevoeligheid voor deze allergenen en hun varianten.
In het onderzoek zijn de genen die bepalend zijn voor de aminozuursamenstelling van de vier belangrijkste allergene eiwitten opgespoord. Daarnaast zijn er genetische merkers ontwikkeld –een soort vlaggetjes waarmee je de aanwezigheid specifieke genen zichtbaar kunt maken-. Met die merkers kun je in kiemplanten al zien of een appel allergene eiwitten zal bevatten. Je hoeft dan niet een paar jaar te wachten tot je een volgroeide, vruchtdragende appelboom hebt.
In het onderzoek werden 26 genen gevonden, waarvan er 18 coderen voor het eiwit Mal d1. Voor patiënten in Noord West Europa wordt Mal d1 als het belangrijkste allergeen van appel beschouwd. Deze patiënten hebben ook last van hooikoorts in het voorjaar als reactie op berkenstuifmeel
Met deze kennis kunnen onderzoekers sneller, met genetische merkers nieuwe, minder allergene appelrassen ontwikkelen. Ook kan men gericht de activiteit van de allergie-genen verminderen. Als dat lukt kunnen appelallergische patiënten in de toekomst een appel eten zonder daar enige last van te krijgen.
De uitkomsten van het onderzoek zijn ook bruikbaar voor genetisch onderzoek in andere fruitsoorten zoals peer en perzik omdat deze overeenkomstige allergenen bevatten.

### *DNA Slimming pill*

**DNA afslankpil**

Op verschillende plaatsen wordt onderzoek gedaan naar de relatie tussen erfelijke kenmerken en vetzucht, of obesitas. Zo hebben Amerikaanse onderzoekers bijvoorbeeld een gen in muizen ontdekt dat codeert voor het hormoon leptine. Muizen die met leptine worden geïnjecteerd verliezen lichaamsvet. Mogelijk speelt dit mechanisme een rol bij mensen met ernstige vormen van obesitas. Als we een bericht in De Telegraaf mogen geloven dan heeft het onderzoek inmiddels geleid tot een toepassing die door iedereen met overgewicht kan worden gebruikt: de DNA-afslankpil.

**Kilo's snel kwijt met dna-pillen**

24 december 2005

*door Martijn Koolhoven*

AMSTERDAM - Aan de vooravond van kerst krijgen Amerika en Nederland een spraakmakende primeur voor mensen die snel op hun ideale gewicht willen komen: de DNA-pil.
Amerikaanse en Nederlandse wetenschappers zijn er na jaren van onderzoek in geslaagd een formule te ontwikkelen waarmee het op basis van iemands persoonlijke DNA mogelijk is een pil te fabriceren waarmee een cliënt binnen enkele maanden zijn ideale gewicht bereikt. De overtollige kilo's verdwijnen, zonder dat men eten of drinken hoeft te laten staan.
Iedere klant krijgt zijn eigen unieke pillen, geproduceerd op basis van zijn eigen DNA. Volgens fabrikant Salugen inc. zijn stofwisseling van de betrokkene en het gewicht gemiddeld binnen drie maanden weer op orde.

*Eventueel voor ná de discussie:*

De Telegraaf Binnenland

Dinsdag 27 december 2005, 08:30

**DNA-afvalpil nu al mateloos populair**

*door een onzer verslaggevers*

DEN HAAG - Tijdens de kerstdagen is er al een run ontstaan op de nieuwe DNA-pil, waarmee het mogelijk wordt om in zo'n drie maanden tijd zonder dieet je ideale gewicht te bereiken.

De Telegraaf berichtte afgelopen zaterdag over deze nieuwe vinding, waar jarenlange research aan vooraf is gegaan en waar door Nederlandse miljonairs meer dan 30 miljoen dollar in is geïnvesteerd. De Amerikaanse tv-ster Oprah Winfrey gaat de pil in haar oudejaarsshow presenteren en neemt daarna zelf de proef op de som.

Zowel dagblad De Telegraaf als de Amerikaanse fabrikant Salugen inc. en het Nederlandse bureau dat in de arm is genomen voor de Nederlandse marktintroductie (ToBeOne in Amsterdam) zijn het afgelopen kerstweekeinde overstelpt met reacties van mensen die zonder dieet van hun overgewicht af willen. De belangstelling voor de nieuwe pil was op een gegeven moment zó groot (13.000 hits) dat de website van Salugen plat ging. Ook de websites van De Telegraaf en van het bureau in Amsterdam moesten alle zeilen bijzetten om de stortvloed aan reacties te verwerken. Sommige mensen denken overigens met een 1-aprilgrap te maken te hebben. Lees verder in De Telegraaf.

# *Appendix 5*
# Survey questionnaire (in Dutch)

Geachte mevrouw, mijnheer,

Wetenschappelijk onderzoek kan leiden tot nieuwe toepassingen. Deze nieuwe toepassingen roepen vaak verschillende soorten reacties op bij mensen. Wij zijn geïnteresseerd in uw mening over één van deze nieuwe toepassingen: genen-onderzoek.

Bij **genen-onderzoek** kunt u denken aan verschillende toepassingen, onder meer op **medisch gebied**. Bekende voorbeelden van genen-onderzoek zijn het onderzoek naar erfelijkheid of het onderzoek naar behandelingsmethoden. Meer toegepaste voorbeelden zijn het gebruik van medicijnen bij het bestrijden van reuma waarbij humane eiwitten betrokken zijn die op kunstmatige wijze zijn gemaakt (zogeheten 'biologicals') of het onderzoek naar het niet verdragen van granen. Ook bij **voedsel** kan genen-onderzoek een rol spelen. U kunt hierbij denken aan voedingsmiddelen die gezonder zijn voor de mens dan reguliere voedingsmiddelen of onderzoek naar het voorkomen van voedselallergieën.

Met de uitkomsten van dit onderzoek willen wij achterhalen hoe verschillende groepen mensen (burgers, patiënten, experts) denken over deze ontwikkelingen en de communicatie hierover verbeteren.

Wij stellen het zeer op prijs dat u de vragenlijst invult. Daarbij is het de bedoeling dat u uw eigen mening weergeeft. Er zijn dus geen "goede" of "foute" antwoorden. Het invullen van de vragenlijst duurt ongeveer 15 minuten. We gaan vertrouwelijk met uw gegevens om, en zullen ze uitsluitend voor dit onderzoek gebruiken.

Hartelijk dank voor uw medewerking!

Anne Dijkstra, onderzoeker Universiteit Twente

De vragenlijst bestaat uit twee delen. In het eerste deel vragen we naar uw opvattingen over aspecten die met genen-onderzoek te maken hebben. In het tweede deel vragen we een aantal achtergrondgegevens, nodig om een analyse te kunnen maken.

DEEL 1

Vraag 1) We willen graag van u weten of u **positief of negatief oordeelt** over elk van de volgende ontwikkelingen. *Wilt u het antwoord aankruisen dat het dichtst bij uw opvatting komt?*

| | Zeer negatief | Een beetje negatief | Niet negatief, niet positief | Een beetje positief | Zeer positief |
|---|---|---|---|---|---|
| Het gebruik van genen-onderzoek bij voedseltoepassingen | ☐ | ☐ | ☐ | ☐ | ☐ |
| Het gebruik van genen-onderzoek om planten en voedingsmiddelen voor de mens gezonder te maken | ☐ | ☐ | ☐ | ☐ | ☐ |
| Het gebruik van genen-onderzoek om voedingsmiddelen te ontwikkelen die ziektes kunnen voorkomen of bestrijden | ☐ | ☐ | ☐ | ☐ | ☐ |
| Het gebruik van genen-onderzoek bij de bestrijding van ziektes | ☐ | ☐ | ☐ | ☐ | ☐ |
| Het gebruik van weefsel van menselijke embryo's voor onderzoek naar behandeling van ziektes | ☐ | ☐ | ☐ | ☐ | ☐ |
| Het gebruik van zogenoemde stamcellen om ziektes te bestrijden. Stamcellen kunnen uitgroeien tot allerlei andere soorten cellen en de functies van die cellen overnemen | ☐ | ☐ | ☐ | ☐ | ☐ |

Vraag 2) Onderstaande uitspraken gaan in op **uw interesse** in genen-onderzoek of toepassingen daarvan. *Kruis aan in hoeverre u het eens bent met de volgende uitspraken.*

Ik heb zeer veel interesse in …

| | Helemaal oneens | Een beetje oneens | Niet oneens, niet eens | Een beetje eens | Helemaal eens |
|---|---|---|---|---|---|
| … de ontwikkeling van medicijnen via genen-onderzoek, zoals toepasbaar bij reuma, of andere erfelijke ziektes | ☐ | ☐ | ☐ | ☐ | ☐ |
| … genetische testen voor het bepalen van erfelijke ziektes | ☐ | ☐ | ☐ | ☐ | ☐ |
| … genen-onderzoek naar de oorzaak of het verloop van erfelijke ziektes als het niet verdragen van granen | ☐ | ☐ | ☐ | ☐ | ☐ |
| … genetische testen voor het opsporen van ziektes die samenhangen met ons voedsel | ☐ | ☐ | ☐ | ☐ | ☐ |
| … de ontwikkeling van voedingsmiddelen via genen-onderzoek, zoals een allergievrije appel | ☐ | ☐ | ☐ | ☐ | ☐ |
| … genen-onderzoek naar de invloed van voedingsmiddelen bij het voorkomen van ziektes | ☐ | ☐ | ☐ | ☐ | ☐ |

De volgende vraag gaat over **uw ervaring** met genen-onderzoek of toepassingen.
*Kruis aan wat voor u van toepassing is, meerdere antwoorden zijn mogelijk.*

Vraag 3) Heeft u wel eens te maken (gehad) met genen-onderzoek of toepassingen?

- ☐ Ja, als patiënt
- ☐ Ja, via mijn werk
- ☐ Ja, via mijn opleiding
- ☐ Ja, als consument bij de aanschaf van producten of diensten
- ☐ Ja, als burger
- ☐ Ja, op een andere manier
- ☐ Nee, nooit

*Kruis aan wat voor u van toepassing is, meerdere antwoorden zijn mogelijk.*
Zo ja, met wat voor soort onderzoek of toepassingen heeft u dan te maken (gehad)?

- ☐ Met onderzoek of toepassingen op voedselgebied
- ☐ Met onderzoek of toepassingen op medisch gebied
- ☐ Met onderzoek of toepassingen op een ander gebied

Vraag 4) *Maak de volgende zinnen af door een van de hokjes aan te kruisen.*

| | Meer weet | Minder weet | Even weinig weet of even veel weet |
|---|---|---|---|
| In vergelijking met andere mensen in mijn omgeving heb ik het idee dat ik **over genen-onderzoek** …. | ☐ | ☐ | ☐ |
| In vergelijking met andere mensen in mijn omgeving heb ik het idee dat ik **over gendiagnostiek**, bijvoorbeeld het voorspellen van een erfelijke afwijking via een test, … | ☐ | ☐ | ☐ |
| In vergelijking met andere mensen in mijn omgeving heb ik het idee dat ik **over voedsel en gezondheid** … | ☐ | ☐ | ☐ |

*Kruis aan wat voor u van toepassing is.*
Vraag 5) Voordat u deze vragenlijst invulde, **heeft u wel eens** …

| | Nee, nog nooit | Ja, een enkele keer | Ja, regelmatig | Ja, vaak |
|---|---|---|---|---|
| …. informatie over genen-onderzoek gelezen, gehoord, of gezien in kranten, op de radio, of op televisie? | ☐ | ☐ | ☐ | ☐ |
| … informatie over genen-onderzoek opgezocht in de bibliotheek of op internet? | ☐ | ☐ | ☐ | ☐ |
| …. Met iemand over genen-onderzoek gepraat? | ☐ | ☐ | ☐ | ☐ |
| …. een bijeenkomst over genen-onderzoek bezocht, zoals een lezing of een publieke hoorzitting? | ☐ | ☐ | ☐ | ☐ |
| …. in een discussiegroep meegedacht over genen-onderzoek? | ☐ | ☐ | ☐ | ☐ |

Vraag 6) Hoeveel **invloed** zou elk van de volgende organisaties of groepen mensen volgens u moeten hebben bij het vaststellen van de grenzen van genen-onderzoek?
*Kruis voor elke organisatie of groep een antwoord aan.*

| | Helemaal geen invloed | Weinig invloed | Enige invloed | Vrij veel invloed | Zeer veel invloed |
|---|---|---|---|---|---|
| Commerciële instellingen als fabrikanten en supermarkten | ☐ | ☐ | ☐ | ☐ | ☐ |
| Ikzelf, vrienden, familie of kennissen | ☐ | ☐ | ☐ | ☐ | ☐ |
| Maatschappelijke organisaties als milieuorganisaties, consumentenorganisaties of patiëntenorganisaties | ☐ | ☐ | ☐ | ☐ | ☐ |
| Wetenschappers die werken voor fabrikanten, de overheid of milieuorganisaties | ☐ | ☐ | ☐ | ☐ | ☐ |
| Wetenschappers die onafhankelijk zijn of werken voor universiteiten | ☐ | ☐ | ☐ | ☐ | ☐ |
| Overheidsinstellingen als ministeries, provincies of gemeenten | ☐ | ☐ | ☐ | ☐ | ☐ |

Vraag 7) *Maak af en kruis aan wat voor u van toepassing is.*
Het **betrekken van burgers** bij beslissingen over grenzen van genen-onderzoek …

| | Helemaal oneens | Een beetje oneens | Niet oneens, niet eens | Een beetje eens | Helemaal eens |
|---|---|---|---|---|---|
| …heeft geen nut omdat de overheid toch al besloten heeft wat ze gaat doen | ☐ | ☐ | ☐ | ☐ | ☐ |
| …zorgt ervoor dat ik meer vertrouwen in de overheid heb | ☐ | ☐ | ☐ | ☐ | ☐ |
| …is verspilling van belastinggeld | ☐ | ☐ | ☐ | ☐ | ☐ |
| …is een goede ontwikkeling | ☐ | ☐ | ☐ | ☐ | ☐ |
| …heeft invloed op de beslissingen van de overheid op dit gebied | ☐ | ☐ | ☐ | ☐ | ☐ |

*Maak de zinnen af en kruis bij elke zin aan wat voor u van toepassing is.*
Vraag 8) Ik **vertrouw** organisaties of groepen mensen, als ….

| | Helemaal geen vertrouwen | Weinig vertrouwen | Enig vertrouwen | Vrij veel vertrouwen | Zeer veel vertrouwen |
|---|---|---|---|---|---|
| … ze de gevolgen van genen-onderzoek op een onafhankelijke manier beoordelen | ☐ | ☐ | ☐ | ☐ | ☐ |
| … ze het genen-onderzoek van verschillende kanten bekijken | ☐ | ☐ | ☐ | ☐ | ☐ |
| … ze duidelijk maken welk belang ze zelf hebben bij genen-onderzoek | ☐ | ☐ | ☐ | ☐ | ☐ |
| … ze verstand hebben van genen-onderzoek | ☐ | ☐ | ☐ | ☐ | ☐ |
| … ze open communiceren over genen-onderzoek | ☐ | ☐ | ☐ | ☐ | ☐ |

Vraag 9) Onderstaande uitspraken gaan in op **de manier waarop u omgaat met informatie** over genen-onderzoek of toepassingen daarvan.
*Kruis aan in hoeverre u het eens bent met de volgende uitspraken.*

| | Helemaal oneens | Een beetje oneens | Niet oneens, niet eens | Een beetje eens | Helemaal eens |
|---|---|---|---|---|---|
| Om mijn mening over genen-onderzoek te kunnen vormen, heb ik veel informatie nodig | ☐ | ☐ | ☐ | ☐ | ☐ |
| Ik vind dat ik als burger veel informatie moet kunnen krijgen over genen-onderzoek | ☐ | ☐ | ☐ | ☐ | ☐ |
| Als ik daar zelf mee te maken heb of krijg, wil ik alles weten over genen-onderzoek | ☐ | ☐ | ☐ | ☐ | ☐ |
| Ik zoek informatie op over genen-onderzoek, bijvoorbeeld over medische toepassingen of over voedseltoepassingen | ☐ | ☐ | ☐ | ☐ | ☐ |
| Als genen-onderzoek discussie in de maatschappij oproept, zoek ik informatie erover op | ☐ | ☐ | ☐ | ☐ | ☐ |
| Als iemand in mijn omgeving met genen-onderzoek te maken heeft of als er iets speelt in mijn omgeving, zoek ik informatie erover op | ☐ | ☐ | ☐ | ☐ | ☐ |

*Kruis voor elke organisatie of groep een antwoord aan.*
Vraag 10) Hoeveel vertrouwen heeft u erin dat de volgende organisaties of personen **eerlijk zijn** over genen-onderzoek?

| | Helemaal geen vertrouwen | Weinig vertrouwen | Enig vertrouwen | Vrij veel vertrouwen | Zeer veel vertrouwen |
|---|---|---|---|---|---|
| Commerciële instellingen als fabrikanten en supermarkten | ☐ | ☐ | ☐ | ☐ | ☐ |
| Vrienden, familie of kennissen | ☐ | ☐ | ☐ | ☐ | ☐ |
| Maatschappelijke organisaties als milieuorganisaties, consumentenorganisaties of patiëntenorganisaties | ☐ | ☐ | ☐ | ☐ | ☐ |
| Wetenschappers die werken voor de overheid, fabrikanten of milieuorganisaties | ☐ | ☐ | ☐ | ☐ | ☐ |
| Wetenschappers die onafhankelijk zijn of werken voor universiteiten | ☐ | ☐ | ☐ | ☐ | ☐ |
| Overheidsinstellingen als ministeries, provincies of gemeenten | ☐ | ☐ | ☐ | ☐ | ☐ |

## DEEL 2 Achtergrond

Vraag 1) In welk jaar bent u geboren?
…..

Vraag 2) Bent u:
☐ Man
☐ Vrouw

Vraag 3) Uit hoeveel personen bestaat uw huishouden, inclusief uzelf?
☐ 1 persoon
☐ 2 personen
☐ 3 personen
☐ 4 personen
☐ 5 personen
☐ 6 of meer personen

Vraag 4) Hoe is de samenstelling van uw huishouden?

☐ Alleenstaand zonder kinderen
☐ Alleenstaand met kinderen
☐ Samenwonend/ getrouwd zonder kinderen
☐ Samenwonend/ getrouwd met kinderen
☐ Thuiswonend bij ouders/ familie
☐ Woongroep/ studentenhuis
☐ Anders

Vraag 5) In het geval dat u thuiswonende kinderen heeft.
Hoe oud is uw jongste thuiswonende kind?

☐ 0 – 5 jaar
☐ 6 – 12 jaar
☐ 13 – 17 jaar
☐ 18 jaar of ouder

Vraag 6) Wat is uw hoogst genoten opleiding, dat wil zeggen voltooid of momenteel mee bezig?

☐ Universiteit (WO)
☐ Hoger beroepsonderwijs (HBO)
☐ HAVO/VWO/Atheneum/Gymnasium/HBS
☐ Middelbaar beroepsonderwijs (MBO)
☐ MAVO (of vergelijkbaar)
☐ Lager beroepsonderwijs (LTS, VMBO of vergelijkbaar)
☐ Lager onderwijs/basisschool

Vraag 7) Bent u werkzaam in een beroep?

☐ Full time (meer dan 20 uur per week)
☐ Part time (20 uur of minder per week)
☐ Studerend
☐ Huisvrouw of huisman
☐ Nee, anders
☐ Weet niet
☐ Full time en studerend
☐ Part time en studerend

Vraag 8) Wilt u de vier cijfers van de postcode van uw woonplaats invullen?

…….

Vraag 9) Hoe maatschappelijk betrokken bent u (in verenigingen, commissies, besturen, vrijwilligerswerk, burenhulp et cetera)?

☐ Helemaal niet betrokken
☐ Nauwelijks betrokken
☐ Betrokken
☐ Erg betrokken
☐ Heel erg betrokken

Vraag 10) Hoe politiek betrokken bent u?

☐ Helemaal niet betrokken
☐ Nauwelijks betrokken
☐ Betrokken
☐ Erg betrokken
☐ Heel erg betrokken

Vraag 11) Kunt u aangeven wat u, over het algemeen genomen, van uw gezondheid vindt?

☐ Uitstekend
☐ Zeer goed
☐ Goed
☐ Matig
☐ Slecht

Vraag 12) En, indien van toepassing. Wat vindt u over het algemeen genomen, van de gezondheidstoestand van uw partner? *Kruis aan wat voor uw partner van toepassing is.*

☐ Uitstekend
☐ Zeer goed
☐ Goed
☐ Matig
☐ Slecht

Voor experts:
Kunt u aangeven aan welk genomics-onderzoeksinstituut u verbonden bent?

☐ Celiac Disease Consortium
☐ Nutrigenomics Consortium
☐ Centre for Medical Systems Biology
☐ Cancer Genomics Centre
☐ VIRGO Consortium
☐ Centre for Biosystems Genomics
☐ Kluyver Centre for Genomics of Industrial Fermentation
☐ Ecogenomics Consortium
☐ Netherlands BioInformatics Centre
☐ Netherlands Proteomics Centre
☐ Maastricht Genome Centre

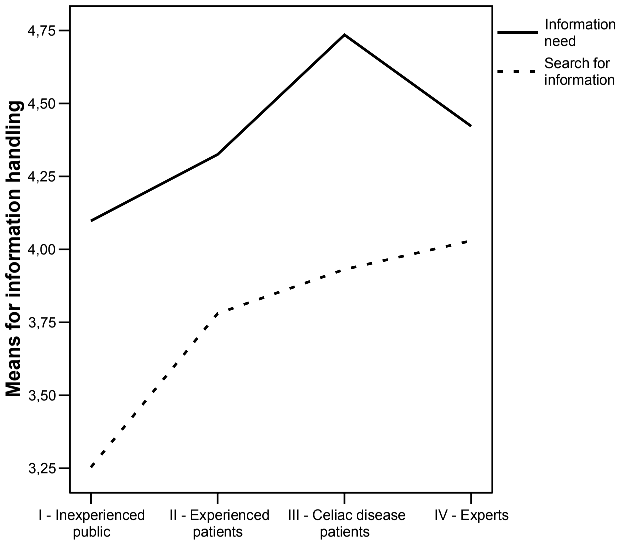
Welke functie bekleedt u bij dit onderzoeksinstituut?
……………………………………………………….

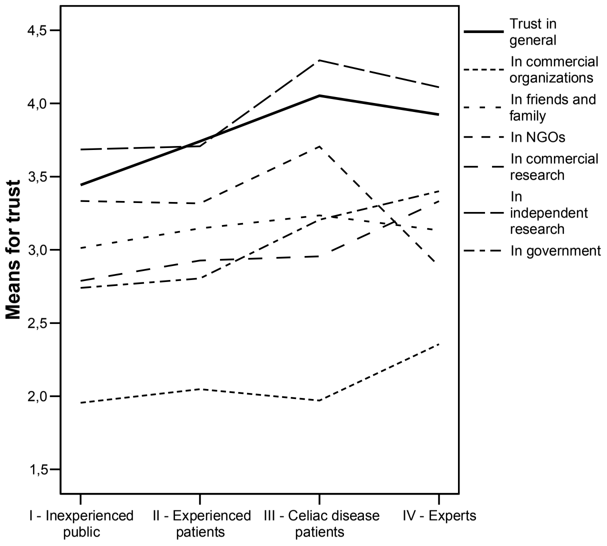
Vraag 13) Tot slot: heeft u in deze vragenlijst zaken gemist?
☐ Nee
☐ Ja, namelijk……………….

U heeft net de vragenlijst afgerond. Dank u wel voor uw medewerking!
Mocht u nog verdere vragen hebben over het onderzoek dan kunt u contact opnemen met:
Anne Dijkstra, onderzoeker Universiteit Twente
e-mail: a.m.dijkstra@utwente.nl
telefoon : 053 489 3316

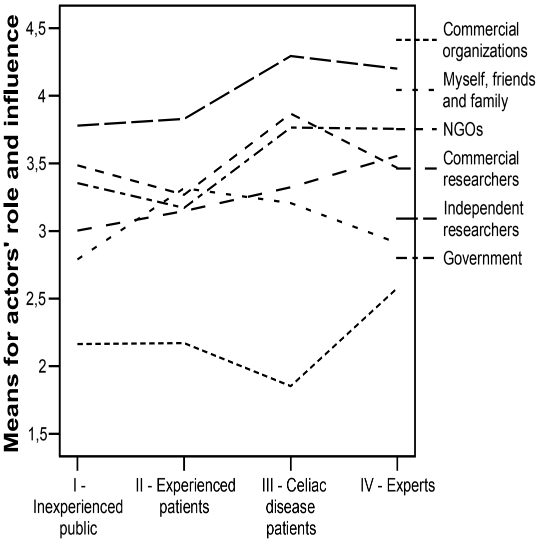
# *Appendix 6*

# Figures of mean scores and correlations matrices


**Means for information need and information-seeking behaviour**


**Trust in general and trust in organizations or groups of people**

**Influence on decision making of organizations or groups of people**



**Means for perception and interest in gene research**

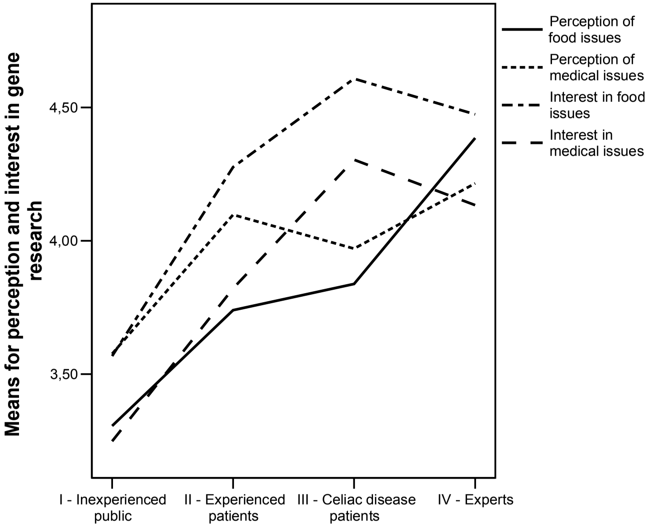


**Table 1: Correlations matrix for passive participating public (Spearman's rho)**

| Inexperienced public (N=986) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Passive participation | 1 | | | | | | | | | | | | | | | | | |
| 2. Active participation | .26** | 1 | | | | | | | | | | | | | | | | |
| 3. Social involvement | .31** | .12** | 1 | | | | | | | | | | | | | | | |
| 4. Citizen's participation | .13** | .05 | .15** | 1 | | | | | | | | | | | | | | |
| 5. Interest food | .33** | .05 | .14** | .24** | 1 | | | | | | | | | | | | | |
| 6. Interest medical | .28** | .01 | .11** | .20** | .82** | 1 | | | | | | | | | | | | |
| 7. Perception food | .13** | .03 | .04 | .12** | .42** | .53** | 1 | | | | | | | | | | | |
| 8. Perception medical | .21** | .01 | .06 | .10** | .49** | .47** | .66** | 1 | | | | | | | | | | |
| 9. Information need | .25** | .02 | .19** | .30** | .37** | .31** | .14** | .20** | 1 | | | | | | | | | |
| 10. Information search | .38** | .06 | .23** | .23** | .36** | .34** | .10** | .16** | .53** | 1 | | | | | | | | |
| 11. Relative knowledge | .36** | .12** | .15** | .07* | .19** | .16** | .06 | .15** | .13** | .22** | 1 | | | | | | | |
| 12. General trust | .24** | .00 | .21** | .31** | .37** | .33** | .35** | .39** | .36** | .25** | .16** | 1 | | | | | | |
| 13. Trust and influence commercial organizations | -.02 | .04 | -.04 | .06 | .04 | .11** | .20** | .07* | -.13** | .03 | -.08* | .03 | 1 | | | | | |
| 14. Trust and influence friends and family | .13** | .06 | -.01 | .35** | .12** | .04 | .00 | .00 | .20** | .14** | .08** | .18** | .01 | 1 | | | | |
| 15. Trust and influence NGOs | .13** | .01 | .20** | .40** | .18** | .16** | .08* | .15** | .31** | .20** | .05 | .42** | -.02 | .30** | 1 | | | |
| 16. Trust and influence commercial researchers | .08* | .05 | .11** | .22** | .18** | .20** | .26** | .23** | .11** | .14** | .04 | .34** | .46** | .06 | .32** | 1 | | |
| 17. Trust and influence independent researchers | .25** | .01 | .23** | .22** | .34** | .32** | .35** | .41** | .34** | .23** | .16** | .55** | -.05 | .07* | .42** | .35** | 1 | |
| 18. Trust and influence government | .05 | .01 | .29** | .29** | .10** | .09** | .15** | .13** | .17** | .10** | .03 | .31** | .16** | .14** | .36** | .37** | .29** | 1 |

** Correlation is significant at the .01 level (2 tailed); * Correlation is significant at the .05 level (2-tailed)

**Table 2: Correlations matrix for active participating publics (Spearman's rho)**

| **Active patients and experts (N=154)** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Passive participation | 1 | | | | | | | | | | | | | | | | | |
| 2. Active participation | .67** | 1 | | | | | | | | | | | | | | | | |
| 3. Social involvement | .07 | -.02 | 1 | | | | | | | | | | | | | | | |
| 4. Citizen's participation | .13 | .01 | .23** | 1 | | | | | | | | | | | | | | |
| 5. Interest food | .07 | -.08 | .10 | .17* | 1 | | | | | | | | | | | | | |
| 6. Interest medical | .06 | .02 | .13 | .10 | .66** | 1 | | | | | | | | | | | | |
| 7. Perception food | .23** | .20* | .01 | .04 | .37** | .57** | 1 | | | | | | | | | | | |
| 8. Perception medical | .12 | .08 | .09 | -.02 | .26** | .30** | .41** | 1 | | | | | | | | | | |
| 9. Information need | .03 | -.08 | .26** | .32** | .35** | .34** | .20* | .02 | 1 | | | | | | | | | |
| 10. Information search | .30** | .18* | .24** | .28** | .40** | .35** | .36** | .22** | .54** | 1 | | | | | | | | |
| 11. Relative knowledge | .72** | .58** | .03 | .14 | .04 | -.04 | .11 | .13 | .05 | .24** | 1 | | | | | | | |
| 12. General trust | .04 | -.12 | .14 | .27** | .20* | .23** | .23** | .16* | .26** | .16 | .12 | 1 | | | | | | |
| 13. Trust and influence commercial organizations | .27** | .18* | -.09 | -.06 | .03 | .08 | .18* | .15 | -.17* | .05 | .18* | -.09 | 1 | | | | | |
| 14. Trust and influence friends and family | -.03 | -.12 | .18* | .33** | .05 | .04 | -.08 | -.05 | .11 | .06 | -.02 | .19* | .09 | 1 | | | | |
| 15. Trust and influence NGOs | -.13 | -.26** | .14 | .35** | .05 | .10 | .04 | -.12 | .18* | .02 | -.19* | .19* | .01 | .27** | 1 | | | |
| 16. Trust and influence commercial researchers | .20** | .15 | .02 | .08 | .11 | .14 | .23** | .16* | -.02 | .06 | .17* | .24** | .43** | .21** | .29** | 1 | | |
| 17. Trust and influence independent researchers | .12 | .02 | .15 | .20* | .15 | .18* | .19* | .24** | .30** | .16 | .17* | .54** | -.03 | .09 | .28** | .31** | 1 | |
| 18. Trust and influence government | .13 | .16 | .15 | .07 | .02 | .16* | .08 | .07 | -.03 | -.07 | .12 | .18** | .11 | -.01 | .23** | .31** | .27** | 1 |

** Correlation is significant at the .01 level (2 tailed); * Correlation is significant at the .05 level (2-tailed).

## *Samenvatting*

# Publiek en wetenschap: over publieke participatie in biotechnologie en gentechnologie

Moet je als wetenschapper vertellen over je onderzoek, ook al zit eigenlijk niemand daarop te wachten? Of kun je je beter concentreren op je onderzoek en laat je die communicatie over aan anderen? In dit onderzoek pleit ik voor het eerste. Als wetenschapper is het belangrijk om over je onderzoek te vertellen; mensen te informeren, maar het gaat verder. Het is ook belangrijk om mensen te betrekken bij je onderzoek; misschien zelfs om mensen invloed te laten uitoefenen op beslissingen over je onderzoek. Maar waarom dan? Het publiek zelf wil dit, concludeer ik in dit proefschrift, ook al lijkt het niet altijd zo. Voor de overheid geldt eigenlijk hetzelfde: het is goed om het publiek bij het onderzoek te betrekken, want ontwikkelingen in wetenschap en techniek kun je niet meer los zien van de maatschappij.

In dit proefschrift onderzoek ik de relatie tussen publiek en wetenschap in het algemeen en de relatie tussen publiek en biotechnologie en gentechnologie (in een mooie Engelse term *genomics* genoemd) in het bijzonder. En dat niet alleen: ik bekijk wat die relatie, volgens het publiek zelf, voor invloed heeft op de gewenste communicatie over biotechnologie, gentechnologie of wetenschap. Ik kijk speciaal naar de relatie tussen publiek en biotechnologie en gentechnologie omdat het voor deze gebieden duidelijk is dat wetenschap en de maatschappij met elkaar verweven zijn. Immers, in het verleden is er, in verhitte debatten, al veel gediscussieerd over biotechnologie en de invloed die ontwikkelingen in dit wetenschapsgebied kunnen hebben op de maatschappij, op mensen zelf.

Het vertrekpunt voor dit onderzoek naar de relatie tussen publiek en wetenschap is literatuur over wetenschapscommunicatie. In deze literatuur bestaan twee modellen over deze relatie. In het zogenoemde *kennis-tekortmodel (deficit model)* gaan onderzoekers ervan uit dat door een tekort aan wetenschappelijke kennis van het algemene en passieve publiek de relatie verslechtert. Daarom is het belangrijk dat dit publiek de belangrijkste kennis wordt onderwezen, in een soort eenrichtingsverkeer. In het zogenoemde *interactieve wetenschapsmodel (interactive science model)* zien onderzoekers dat anders.

Het publiek wil actief betrokken worden bij de ontwikkelingen en beslissingen over wetenschap en kan daarin bijdragen met haar eigen kennis. Wetenschappelijke kennis is daarvoor niet perse nodig. Belangrijk is dat de communicatie een tweerichtingskarakter heeft en dat er een dialoog tussen actief publiek en wetenschap plaatsvindt.

Een factor die het huidige onderzoek bemoeilijkt is dat de aanhangers van de beide modellen lijnrecht tegenover elkaar staan en niet nader tot elkaar lijken te kunnen komen. Dit blijkt ook uit de methodes die in het bestaande onderzoek worden gebruikt: in kwantitatieve onderzoeken wordt het kennistekort van het passieve publiek geconstateerd en in kwalitatieve onderzoeken wordt gevonden dat het publiek actief mee wil beslissen over wetenschap.

Om deze problemen te omzeilen heb ik in dit proefschrift verschillende onderzoeksmethoden, kwantitatief en kwalitatief, gebruikt in drie empirische studies die de relatie tussen publiek en biotechnologie of gentechnologie bestuderen. Bovendien heb ik geen keuze gemaakt voor één van de twee modellen als startpunt, maar ben begonnen met de belangrijkste achterliggende concepten die in beide modellen van belang zijn. Vanuit deze concepten, namelijk het denken over passief en actief publiek, het belang van wetenschappelijke kennis, de rol van informatie en communicatie, en de rol van vertrouwen in deze relatie, heb ik mijn onderzoek uitgevoerd. Door deze aanpak hoop ik bij te kunnen dragen aan meer begrip over de relatie tussen publiek en wetenschap, hoop ik meer theoretisch begrip te krijgen over de concepten die in deze relatie een rol spelen en in de modellen van belang zijn, en uiteindelijk hoop ik dat mijn resultaten kunnen worden vertaald naar concrete communicatieadviezen.

In *hoofdstuk 1* presenteer ik de context voor de empirische studies. Ik beschrijf de belangrijkste motieven voor wetenschapscommunicatie in Nederland en vergelijk deze met de motieven in bijvoorbeeld Engeland. Ik geef een overzicht van de Nederlandse politieke en juridische achtergrond van biotechnologie en gentechnologie. Tot slot beschrijf ik opvattingen en meningen van het Nederlandse publiek over wetenschap en technologie in het algemeen en over biotechnologie en gentechnologie in het bijzonder.

In *hoofdstuk 2* ga ik dieper in op de twee theoretische modellen en de ontwikkelingen in de literatuur over wetenschapscommunicatie. Daarbij neem ik relevante bevindingen uit de risicocommunicatie, de gezondheidscommunicatie en de publieke participatie mee. Aan het eind van het hoofdstuk bespreek ik de belangrijkste concepten die de basis vormen van het empirische onderzoek.

In *hoofdstuk 3* bespreek ik methodische aspecten. Ik beargumenteer niet alleen dat het combineren van meerdere methodes de problemen tussen de twee modellen omzeilt, maar vooral ook dat het gebruik van meerdere onderzoeksmethoden tot een uitgebreider beeld van de relatie tussen publiek en wetenschap leidt.

In *hoofdstuk 4* beschrijf ik het eerste onderzoek: een kwalitatieve analyse van documenten over vijf Nederlandse biotechnologiedebatten die van 1993 tot en met 2001 zijn gehouden. Aan de orde komen analyse van de rollen van het algemeen publiek in die debatten en de rol van de wetenschap; het belang van wetenschappelijke kennis; de communicatie- en participatiemiddelen, en de rol van vertrouwen in wetenschap. Uit de resultaten blijkt dat het algemeen publiek verschillende rollen vervult in de biotechnologie debatten. Het grootste deel van het publiek blijft passief, een klein deel van het publiek participeert actief in de debatten. De invloed van het publiek op het beslissingsproces is gering: de uitkomsten van debatten worden aangeboden aan parlementsleden en kunnen worden meegenomen in het beslissingsproces. In de debatten vindt de communicatie plaats volgens eenrichtings- en tweerichtingsprocessen. De tweerichtingsprocessen zijn erop gericht om het publiek te laten participeren, maar soms wordt die mogelijkheid tot participatie verminderd tot het alleen mogen laten horen van opvattingen over onderwerpen die door de organisatoren zijn gekozen. Tot slot veranderen de opvattingen over wetenschappelijke kennis en vertrouwen tijdens de debatten. In de eerste debatten wordt vertrouwen als iets vanzelfsprekends gezien en gaat het erom dat mensen door deelname meer wetenschappelijke kennis over het onderwerp krijgen. In de latere debatten ligt de nadruk op het wekken van vertrouwen en spelen andere soorten kennis en emotie naast wetenschappelijke kennis een rol.

In *hoofdstuk 5* presenteer ik de resultaten van groepsdiscussies met mensen in verschillende rollen. Groepen van zes tot tien personen discussieerden over hun betrokkenheid bij genenonderzoek, de rol van wetenschappelijke kennis, de soort informatie of communicatie die zij wenselijk achtten, en de invloed die ze hebben of zouden willen hebben op genenonderzoek en het vertrouwen in betrokkenen bij genenonderzoek. De groepen bestonden uit mensen in hun rol als algemeen publiek (niets te maken met genenonderzoek, dus onervaren publiek), actieve consumenten (lid van het ledenparlement van de Consumentenbond), reumapatiënten (kunnen medicijnen slikken die met gentechnologie zijn geproduceerd), coeliakiepatiënten (via genenonderzoek kan wellicht meer bekendheid over hun ziekte worden verkregen), voedselexperts (werken in de voedselsector en hebben gentechnologie in hun takenpakket) of medische experts (werken in de medische sector en hebben gentechnologie hun takenpakket).

Uit de gesprekken bleek dat mensen in alle rollen hun interesse beperken tot onderwerpen waar ze persoonlijk bij betrokken raken of zijn. Verder vinden alle groepen communicatie meer inhouden dan alleen informatie verspreiden, maar kennis speelt wel een belangrijke rol. Veel informatie die beschikbaar komt vinden mensen vertekend; daarom pleitten ze voor transparantie in de communicatie en openheid over bronnen. De groepen verschillen van mening over de vorm van communicatie. Het niet-ervaren publiek wil informatie ter beschikking hebben, ook al gebruikt het die niet actief; in sommige gevallen wil het ook actiever betrokken worden bij genenonderzoek. Actieve consumenten benadrukten de noodzaak om te luisteren naar het publiek. Patiënten gaven zich een meer actieve rol in het communicatieproces: ze lichten anderen voor over hun ziekte of ze zoeken manieren om te kunnen meepraten en meebeslissen over het onderzoek. Kortom: in de meer georganiseerde groepen zijn mensen in staat zich te ontwikkelen en zich een actieve rol in het wetenschaps- en technologiedebat toe te bedelen. Ondertussen wijzen experts vooral op het nut om wetenschappelijke kennis te onderwijzen aan een algemener publiek.

De groepen verschillen van mening over de invloed op beslissingen over genenonderzoek. Het onervaren publiek wil geen invloed of denkt geen invloed te hebben. Zowel actieve consumenten als beide patiëntengroepen denken wel enige invloed te kunnen uitoefenen, via hun organisatie. Beide groepen experts geven aan dat hun invloed onderdeel is van een groter beslissingsproces. Iedereen is het erover eens dat de industrie de meeste invloed heeft op genenonderzoek. Dat is ook de reden dat de invloed van andere actoren, bijvoorbeeld van non-profit organisaties, nodig is en dat controlemechanismes als gecontroleerde ontwikkeling en controleerbaarheid en openheid van onderzoek en onderzoeksresultaten van belang zijn.

Tot slot benadrukken groepen in alle rollen het belang van vertrouwen – of eigenlijk het ontbreken van vertrouwen. Het is nodig om het vertrouwen te herstellen en manieren daarvoor worden gesuggereerd: openheid van bronnen, duidelijkheid over belangen van betrokken actoren, transparantie in de communicatie en solidariteit. Ook experts wijzen op hun dalende vertrouwen, met name in de industrie en stemmen in met de genoemde mogelijkheden om vertrouwen te herstellen.

In *hoofdstuk 6* geef ik de resultaten weer van het derde empirische onderzoek, een vragenlijst voorgelegd aan groepen in de rol van onervaren publiek (representatief voor de Nederlandse bevolking), ervaren patiënten, coeliakiepatiënten en experts werkzaam in genenonderzoek. Mensen in deze verschillende rollen participeren op verschillende manieren in genenonderzoek. Het onervaren publiek participeert niet en kan worden beschouwd als een passief publiek. De andere groepen zijn actiever waarbij experts het meest actief betrokken zijn bij genenonderzoek. Deze passieve en actieve publieken verschillen in aspecten over genenonderzoek. Zo toont het onervaren publiek, het passieve publiek, bijvoorbeeld minder interesse in genenonderzoek en schat het de eigen kennis over genenonderzoek lager in dan de meer actieve publieken. Echter, er is geen verschil tussen de publieken als het gaat om bijvoorbeeld politieke en sociale betrokkenheid in het algemeen. De actieve publieken verschillen ook onderling. Zo hebben patiënten dezelfde mening als experts over hun zoekgedrag naar informatie, en hebben patiënten dezelfde mening als het onervaren publiek over hun vertrouwen in actoren en de invloed die die actoren zouden moeten hebben. Het informatiezoekgedrag, samen met de geschatte relatieve kennis over genenonderzoek en het opleidingsniveau en de sociale betrokkenheid zijn factoren die passieve participatie beïnvloeden, terwijl de geschatte relatieve kennis en sekse bijdragen aan een actieve rol. En, in tegenstelling tot wat men zou verwachten, komt vertrouwen niet als factor van belang uit de analyse.

In het slothoofdstuk, *hoofdstuk 7*, bespreek ik wat de resultaten betekenen voor de gekozen uitgangspunten bij de start van het onderzoek. De resultaten samen geven een genuanceerd en uitgebreid beeld van het publiek en zijn relatie met wetenschap en techniek. Als eerste trek ik de conclusie dat het onervaren publiek een passief publiek is dat niet betrokken is bij biotechnologie of gentechnologie. Er bestaan wel kleine groepen actieve publieken; dat zijn mensen die betrokken zijn als de noodzaak er is. Patiënten en actieve consumenten zijn hiervan voorbeelden. Experts hebben een actieve rol, maar dat geldt alleen voor hun eigen expertisegebied. Op andere gebieden zijn ze vergelijkbaar met het onervaren publiek. Er bestaan dus publieken in verschillende rollen. Die publieken zijn meer of minder betrokken in genenonderzoek. Publieken met een specifieke rol gedragen zich actiever dan het meer algemene en passieve publiek. In vergelijking met de theoretische modellen zijn er dus zowel passieve publieken zoals het 'deficit model' aangeeft als actieve publieken zoals in het 'interactive science model'.

De tweede conclusie is dat wetenschappelijke kennis een belangrijke rol speelt, maar alleen in bepaalde situaties. Volgens experts kunnen mensen ook zonder deze kennis redelijke beslissingen nemen. Meer kennis leidt niet automatisch tot meer interesse in genenonderzoek.

Het idee van neutrale kennis is verlaten en wetenschappelijke kennis wordt meer gezien als een type kennis waar ook emoties een rol hebben binnen een sociale en politieke context.

Een derde conclusie is dat informatie en communicatie erg belangrijk worden gevonden door de verschillende publieken. In alle rollen willen mensen dat informatie beschikbaar is, ook al doen ze er niet altijd wat mee. Experts zijn het hiermee eens. Volgens hen reageren mensen verschillend op informatie. Soms kan de communicatie met het publiek plaatsvinden in eenrichtingsprocessen, soms kan dit beter in tweerichtingsprocessen. In alle gevallen worden er wel wat voorwaarden gesteld aan de informatie: de informatie moet niet vertekend zijn, maar belangen en interesses van de zenders moeten duidelijk zijn. Dit zijn ook voorwaarden om vertrouwen te wekken tussen publieken en wetenschap.

Een vierde conclusie die ik trek is dat vertrouwen een belangrijke rol speelt zoals in het ‘interactive science model’ wordt gesuggereerd. Het publiek ziet vertrouwen als een manier om betrokkenheid bij een onderwerp te delegeren. Manieren om aan vertrouwen te werken zijn openheid en transparantie in informatie en het gebruik van meerdere bronnen van informatie. Het meest worden nog altijd wetenschappers vertrouwd. Tegelijk wordt duidelijk dat vertrouwen en kennis gerelateerd zijn. En de mate van invloed speelt een rol in het vertrouwen in een organisatie. Hoe meer invloed, hoe minder vertrouwen.

Samengevat geven de resultaten een goed inzicht in de relatie tussen publiek en wetenschap. Een belangrijk inzicht is dat de rol van de ontvanger, het publiek zelf, ertoe doet. Mensen hebben verschillende rollen en bij veranderingen van rollen verandert ook de behoefte aan communicatie. Het onderzoek heeft geleid tot meer inzicht in de aard van deze rollen. Daarnaast zijn bestaande inzichten bevestigd, zoals het belang van wetenschappelijke kennis en de rol van informeren. Tegelijk zijn nieuwe inzichten verkregen, bijvoorbeeld over de rol van andere soorten kennis en de rol van vertrouwen in de relatie.

Vanuit een theoretisch perspectief leiden de resultaten tot de conclusie dat beide modellen niet volledig de lading dekken wat betreft de relatie tussen publiek en wetenschap. Beide modellen vullen elkaar eerder aan dan dat ze elkaar uitsluiten. Door het onderzoek te laten vertrekken vanuit de concepten is meer inzicht in de relatie en de positie van de concepten verkregen.

Ook heeft de keuze voor meerdere onderzoeksmethoden aan meer inzicht bijgedragen. De drie onderzoeken zouden elk op zich een minder genuanceerd beeld hebben laten zien. Dit blijkt bijvoorbeeld uit de bevindingen over het passieve en actieve publiek. De combinatie van de methoden toont dat actief publiek betrokken wil worden bij genenonderzoek. Deze betrokkenheid blijft echter beperkt tot een paar onderwerpen; het grootste gedeelte van het publiek is een passief publiek, dat dan wel weer geïnformeerd wil worden. Verder grijpt elk onderzoek op elkaar in doordat resultaten van de onderzoeken zijn gebruikt voor de latere onderzoeken. Daardoor heeft elke methode een evengrote inbreng in de slotconclusie. Tot slot is door de keuze voor meerdere methoden de polemiek rond de twee modellen omzeild.

Wat kun je nu met de bevindingen? In de laatste paragrafen van dit proefschrift geef ik suggesties voor vervolgonderzoek. Ook bespreek ik een paar mogelijkheden voor toepassing in de praktijk van de wetenschapscommunicatie.

Vervolgonderzoek zou zich kunnen richten op de modellen en kan proberen deze te verfijnen. Daarbinnen is aandacht voor de rollen die mensen hebben van belang, hoe deze rollen veranderen en wat dat betekent voor de door hen gewenste communicatie. Ik noem nog drie andere thema's voor onderzoek. Als eerste, waarom en wanneer mensen actief willen participeren in wetenschap en technologische onderwerpen, zeg maar het brede thema van burgerschap. Als tweede, hoe transparantie en openheid van informatie en communicatie kan worden gegeven, bijvoorbeeld via popularisatie van wetenschap en technologie. Als derde verdient de rol van vertrouwen in de communicatie over wetenschap en technologie nadere bestudering. De Universiteit Twente start in het najaar van 2008 met een nieuwe Masteropleiding Science Communication waar ook de mogelijkheid tot onderzoek op deze thema's zal worden bekeken.

Voor de praktijk suggereer ik dat communicatie zich niet moet beperken tot informeren. Ook het aanbieden van mogelijkheden tot actieve participatie zijn belangrijk, want er zijn altijd mensen, in wisselende groepen, die dat willen en dat zelfs eisen. Dat vereist een proactieve rol van zowel onderzoekers als overheid. Wetenschappers worden het meest vertrouwd en kunnen daarom bijdragen aan openheid en transparantie in deze communicatie en hiermee ook aan het herstel van vertrouwen in wetenschap en technologie. Wetenschappers kunnen bruggen bouwen tussen wetenschap en maatschappij. Maar deze communicatie hoeft niet altijd tweerichtingscommunicatie te zijn; dat is niet altijd wat het publiek wenst. Ik geef ook aan dat volgens het onderzoek het publiek de overheid ook een belangrijke rol toebedeelt. De overheid wil dat publiek participeert, en ondanks dat maar een klein deel van het publiek dat actief doet, is het toch van belang om de mogelijkheid te blijven geven en het publiek te blijven informeren over wetenschappelijke en technologische ontwikkelingen.

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# *Curriculum Vitae*

Anne M. Dijkstra (1967) haalde haar VWO diploma in 1986 (Gomarus College Groningen). Daarna reisde ze een jaar, waarna ze begon met de studie Farmacie (Rijksuniversiteit Groningen). Ze stapte over naar de opleiding Communicatie en Management en haalde haar diploma in 1992 (Toegepaste HuishoudWetenschappen, Hanzehogeschool Groningen). In 1994 haalde ze haar diploma Communicatiekunde (Rijksuniversiteit Groningen). Vervolgens werkte ze enige jaren als wetenschapsvoorlichter en persvoorlichter aan de Universiteit Twente. Vanaf 1999 was ze projectleider en senior communicatieadviseur bij Stichting Weten in Utrecht. Ze kwam terug bij de Universiteit Twente als docent en begon in 2003 aan haar promotieonderzoek. Tijdens haar onderzoek heeft ze adviezen gegeven voor de nieuwe Masteropleiding op het gebied van de wetenschapscommunicatie. Op dit moment is ze als universitair docent betrokken bij de start van deze Master Science Education and Communication.

Anne M. Dijkstra (1967) completed her secondary education in 1986. She traveled for a year and started to study Pharmacy. She switched to Communication and Management at the Hanzehogeschool Groningen and received her Bachelors degree in 1992. In 1994 she got her Master's degree Communication Sciences (University of Groningen). Subsequently, she worked as a science information and press officer at the University of Twente. Thereupon, she worked as a project leader and senior communication advisor for Stichting Weten in Utrecht. She returned to the University of Twente as a teacher and started her research project in 2003. During her project she was involved in the design of the new Master's program Science Education and Communication. At the moment she is working as an assistant professor for this new Master.