



# SCIENTIFIC AUTHORITY IN DECLINE?

The discussion about the HPV-vaccination viewed  
through the eyes of the stakeholders

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## **ABSTRACT**

Over the last couple of years there were, nationally, as well as internationally, several controversial cases in which science or scientists were under fire. Characteristic for these cases is that the discussion had repercussions on science as a whole. Some public experts even claim that the authority of science is waning.

However, the question is what really is at stake in these cases and whether it is scientific authority in decline or if something else is going on. This study deals with this question from the perspective of stakeholders and investigates what they construct as being at stake in a case where scientific authority seems to be in decline. These stakeholder views, and the differences between stakeholders, will be used to explain the origin of the discussion and give insight in what role scientific authority played according to the stakeholders.

The case used for this study is the discussion about the introduction of the HPV-vaccination, a vaccination for twelve-year old girls against a group of viruses that cause cervical cancer. The discussion about the vaccination has been fierce and it is often used as an example of scientific authority in decline. The method used to explore the views of the stakeholders in the discussion about the HPV-vaccination is that of semi-structured interviews.

Literature on the role of science in society shows that there are many aspects that play a role in the troubled relation between scientific experts and the public. The theoretical framework gives an overview of what might be at stake in a discussion where scientific authority seems to be in disrepute, along with the solutions that are mentioned to improve the relation between public experts and the public.

The interview results show that there are several causes defined for the discussion. The opinions of anti-vaccination movements are dismissed as non-scientific, while they want to join the scientific discussion. One-sided government communication has led to irritation among anti-vaccination movements. Public communication of the vaccine producers has led to suspicion among the public. Furthermore the decline of scientific authority seems to be a way for public experts to describe the diminishing of the self-evident authority that used to flow from their status as expert.

The results reveal the need for a discussion on what is expected from scientific authority in cases such as the HPV-vaccination and what role scientific experts should play in the decision-making process. Furthermore public experts should work on building trustworthiness instead of merely pointing to deficits of the public. A final important implication is that vaccine producers should reflect on their own role in causing the discussion, something that has been lacking so far.



## **PREFACE**

The thesis you are holding is the result of my work of the past eight months. I have written this master thesis as a part of my Master Science Communication at the University of Twente. The subject of this thesis was chosen after deliberation with my first supervisor Hedwig te Molder. It started with my own preference for a topic that had “something to do with media” and evolved from negative reports in the news about science and fraudulent scientists, to the decline of scientific authority and a qualitative study on the discussion about the HPV-vaccination. It is a subject that has excited me more and more as my research progressed. Now, after nearly eight months, ten interviews and almost 150 pages of interview transcripts, I can say that I am proud of the final end result.

Despite my limited background in qualitative research, the entire process has been a positive and smooth learning experience. I should thank Hedwig for this, because she possesses the quality to motivate me, with her comments and feedback, to get back to work in good spirits, over and over again. Thank you for that! In addition, I would like to thank my second assessor, Erwin van Rijswoud, for his commitment and insights, always willing to exchange ideas or to give helpful advice before an interview. Furthermore, I would like to thank Anne Dijkstra for setting up the Science Communication Master and making it a success, and of course also for all the lunches and walks during the last couple of months. Finally, I would also like to thank Pauline Teppich for a cheerful start and end of every working day!

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# **1. INTRODUCTION**

## **1.1 BACKGROUND**

Looking at news stories from the past couple of years, it appears that there is a discussion going on about the role of science in our society. For instance in March 2009, only sixty percent of the twelve-year-old girls who were called up, went to get the HPV-vaccination against cervical cancer (ANP, 2009). This low vaccine uptake occurred in spite of the recommendation of the Dutch Health Council, which had formed a committee consisting of scientists and gave the advice to include the vaccine in the National Vaccination Program. Countering this advice a couple of civil movements campaigned against the HPV-vaccination. In his Machiavelli reading, Roel Coutinho of the National Institute for Public Health and Environment, complained about the opinion of a florist, which represented one of the movements, being valued equal to the opinion of scientists (Coutinho, 2010).

In a more recent example (August 2011) research showed that meat eaters are selfish and less social (DePers, 2011). This led to a discussion about the researcher, social psychologist Roos Vonk, who was chairman of Wakker Dier from 2005 to 2008. The results seemed to fit her beliefs as a vegetarian and therefore the validity of the results was questioned, (e.g. KromKrommer, 2011). Two weeks later it was announced that part of the data for this research were made up by her research partner, professor Diederik Stapel (Hoevenaars, 2011). It turned out that his fraud did not limit itself to just this study, but a committee consisting of several professors concluded that he committed large-scale, long-term fraud with data and that Stapel had violated the integrity of science as a whole (Commissie-Levelt, 2011). This unveiling caused a wide discussion in the media about the role of science in society, in which one columnist even stated, somewhat provocatively, that 'science is just an opinion'. In his column he explains that since the Stapel affair he thinks twice before simply believing scientific results that reach the headlines of the news (Pam, 2011).

A final example comes from September 2011, when research by Wageningen UR about possible benefits of drinking milk was countered by animal rights organization Wakker Dier, which started a test case against the University (ANP, 2011). Wakker Dier claimed that the University was influenced by the dairy industry, which funded the research (Wakker Dier, 2011). This case led to a broader discussion about the objectivity of research funded by the industry (e.g. EenVandaag (2011)).

Scientific findings leading to public discussions is a phenomenon of all time, think for instance of the discussions about nuclear energy or GM food. Anti-vaccination movements also have existed for over a century, so there is nothing new in that respect. When it comes to the fierceness and scope of the discussion however, there is a new trend visible. In all three cases above the

discussion did not limit itself to the subject of the research or to the scientists that were responsible for the research. The cases all led to broader discussions about the credibility of science and scientists and the role of science in our society. A common theme in these broader discussions is that of the authority of science being in decline. The title of the earlier mentioned Machiavelli reading of Roel Coutinho was ‘The authority of science under attack’ and the thrust of this reading is that the once so self-evident authority of science is currently waning. In her inaugural address at the University of Twente, Professor of Science Communication Hedwig te Molder states that ‘it looks as if science is under attack from all sides’ (te Molder, 2011). She uses several examples to show that it appears as if the times that experts are unquestioningly believed, because they carry the label of “scientific expert”, are long gone. She argues that the apparent opposition is not simply rooted in a dislike of science and experts, but that there is more going on in the dynamics between science and society. A final example of the topicality of the subject of scientific authority being in decline is the publication at the end of 2011 by philosopher of science Huub Dijstelbloem and political scientist Rob Hagendijk. In their book different authors explore if the worries of public experts, like Roel Coutinho, about the authority of scientific experts are justified (Dijstelbloem & Hagendijk, 2011). The content of the book is discussed in the next chapter.

## **1.2 RESEARCH QUESTION**

So apparently scientific authority seems to be in decline; however the question remains what really is at stake in these cases and whether it is scientific authority in decline or if something else is going on. This thesis deals with this question from the perspective of stakeholders. Do the stakeholders in a case where scientific authority seems to be waning also perceive this supposed ‘decline’, or do they experience the situation differently? And if there’s a difference, what underlies this difference in perception?

It can make a difference who defines the issue as an authority problem. For instance if the problem is mainly recognized by public experts who expect, or maybe even demand to have a certain authority, they implicitly put the origin of the problem with the public that does not seem to acknowledge their authority anymore. As a result the solution to the problem also lies with public, who are expected to accept that scientists have a certain authority.

This thesis will investigate how different stakeholders define the issue in a case where scientific authority seems to be in disrepute. These stakeholder views will be used to explain the origin of the discussion and give insight in what role scientific authority played according to the stakeholders. The purpose of this study is to find out, from the perspective of the stakeholders themselves, what is going on in the discussion and to what extent a decline of scientific authority played a role. The research questions that this research will try to answer are:

1. *How do the stakeholders construct the discussion in a case where scientific authority seems to be in disrepute?*
2. *How do the stakeholders view the role of scientific experts and expertise in a case where scientific authority seems in disrepute?*

### **1.3 CASE**

The case that will be used for this research is that of the discussion about the introduction of the HPV-vaccination, as mentioned at the start of this chapter. First of all this case is selected because it is treated by many as an example of the apparent decline of scientific authority (e.g. te Molder, 2011, Dijstelbloem & Hagendijk, Coutinho, 2010). Secondly, it caused a broad discussion among the public and finally because it is a discussion in which ‘the public’ faces ‘the authorities’ and more specifically the scientific experts whose authority seems to be at stake. In Chapter 3 the choice is further elaborated, meanwhile this section gives a concise description of the events that occurred in the case. A more extensive overview of the case is given by Van Rijswoud (2012).

In September 2006 the first vaccines against the Human Papilloma Virus (HPV) that causes cervical cancer became available (RIVM, GGD Nederland, & NVI, 2010). At the end of March 2008 the Dutch Health Council advised the Ministry of Health, Welfare and Sport (VWS) to include the vaccine in the National Vaccination Program (RVP). This decision was based on seven criteria and was elaborated in a report for the Ministry (Gezondheidsraad, 2008). The advice stated that the vaccine should be issued to girls of twelve years of age, because it is argued that there is a higher chance of success if the vaccine is given before the girls are engaged in sexual activities. In November 2008 the Minister of VWS decided to include the vaccine in the program and as a result the first group of girls was called up in February 2009 to get the first of three vaccination shots. Up to the moment when the Health Council was commissioned to form an advice, stakeholders were promoting the uptake of the vaccine in the RVP, but meanwhile a heated debate about the HPV-vaccination had begun (van Rijswoud, 2012). Distressed mothers doubted the working of the vaccine, called for more research on the risks of the vaccine and questioned the reasons behind the perceived rush of the government to get the vaccination campaign started (Bleeker, 2010). But not only mothers opposed the actions of the Ministry of VWS. Opinion formers, researchers from the Erasmus University and the Dutch Cancer Institute were critical of the introduction of the vaccine. (Consumentenbond, 2009; de Kok, Habbema, Mourits, Coebergh, & van Leeuwen, 2008; van Maanen, 2007). In online communities the resistance against the vaccination campaign grew and horror stories about possible side effects emerged (e.g. TROS Radar (2009)). Regardless of the fact whether these stories are true or not and whether the critiques are valid or not, only sixty percent of the target population got vaccinated. This was much lower than the seventy-five percent the RIVM and Health Council expected. The RIVM reacted by stating that the information on anti-vaccinations website was false and

dismissed the horror stories as old wives' tales, that should not be taken seriously (NOVA, 2009). Despite this attempt to calm the tempers the vaccine uptake for the vaccination did not rise. A total of fifty-six percent of the 2009-group collected all three vaccination shots and so far also fifty-six of the 2010-group has collected two shots (RIVM, 2011).

## 1.4 AIMS

Although at this moment, at the time of the HPV-campaign of 2012, the discussion about the HPV-vaccination does not get as much attention as at the time of the introduction anymore, several stakeholders are still involved in the discussion. The government has to approach a new group of girls each year and anti-vaccination movements continue to spread information against vaccination. The aim of this research is therefore to form a basis for a more fruitful discussion about the HPV-vaccination, by providing insight in the origin of the discussion. This insight is obtained by **comparing the views** of the stakeholders and can help to understand the **motives the different stakeholders have for joining the discussion**.

Because it is not clear what is going on with respect to the decline of scientific authority, a second aim is to find **out to what extent a decline of scientific authority played a role** in the discussion and what the result is of defining the issue as an authority problem. These insights could help understand why certain stakeholders define a decline of authority and what implications this has for the role scientific experts.

## 1.5 THESIS OUTLINE

This chapter formed an introduction on the subject of this thesis and should provide the reader with an understanding of the issue and the relevancy of the topics that are under investigation. Chapter 2 discusses literature on the role of scientific expertise in society and gives a provisional answer to what might be going on in discussions where scientific authority seems to be in disrepute. At the end of the chapter the two research questions posed in section 1.2, are further specified. The method that was used to find an answer to these questions is described in Chapter 3. Chapter 4 provides the results of the research and finally Chapter 5 discusses the conclusions that can be drawn from the results, along with the implications these conclusions have for the participatory stakeholders. Finally the limitations of the current research are set forth, together with recommendations for further research.

## **2 THEORETICAL FRAMEWORK**

The main question that this research tries to answer is: what is going on in a case where scientific authority seems to be contested? In the introduction of this thesis it was pointed out that the decline of scientific authority seems to be a phenomenon of these days and therefore answers to the question what's going on, should also give an explanation why this problem emerges now. This chapter gives an overview of the answers to these questions that can be found in the literature, but first a closer look is taken at the definition of authority to get a clear view of what we are talking about when we speak of scientific authority.

### **2.1 AUTHORITY**

Before consulting literature for answers to the main question of this study, it is useful to find out what is understood by the term 'authority'. Two often cited definitions come from famous sociologists Herbert Simon and Max Weber. The first is given by Simon (1946, p54):

*"A subordinate may be said to accept authority whenever he permits his behavior to be guided by a decision reached by another, irrespective of his own judgment as to the merits of that decision."*

In the case of scientific authority this could be explained as scientists having the power to influence the behavior of other people, without them questioning the reasoning of the scientists. The second definition comes from Weber (1947) cited by Caporaso (2000, p6):

*"In Weber's (1947) famous definition, authority is power wielded legitimately. Authority refers to the structure of rule (Herrschaft) in which the commands of the ruler are accepted as legitimate. In this formulation, power [...] is attached to legitimacy to form a conceptual compound, authority."*

This largely corresponds with the other definition, only here it is made explicit that the decisions have to be accepted as legitimate, so for power to be authoritative it has to be accepted as legitimate.

### **2.2 SCIENTIFIC EXPERTS IN SOCIETY**

The previous section shows that authority can be viewed as a form of power that has been accepted as legitimate. If scientific authority is in decline, this can be explained as the public no longer accepting the claims of scientists as legitimate. This implies that the grounds from which scientists derive their authority are no longer accepted as legitimate. Historian of science Steven Shapin (2008) describes how since the occupation of scientist came into existence in the seventeenth century, the motives attributed to scientists have been changing throughout the centuries. The early scientists were considered "priests of nature", who contemplated the works of God. Those who studied nature were assumed to have qualities that distinguished them from ordinary people and even making them *better* than ordinary people. Although only gentleman

became scientists at that time, researching nature was not well respected and had to be justified, for instance by linking it to Christian fashion.

During the eighteenth and nineteenth century, as the outcomes of scientific research turned out to be useful for politics and industries, science became more integrated with these structures. Most scientists however, remained amateurs. During the nineteenth century a distinction arose between “pure sciences” and “applied sciences”. The latter were profitable through patents, but the former were at the time excluded from reward. Scientists celebrated the civic worth of their research, abandoning the justifications that were needed before.

In the late nineteenth century, scientific research became separated from the divine and shifted to the secular domain. This was the beginning of the transition of science as a calling to science as a job, which took place into the twentieth century. Scientists were no longer different from other people, but gained their credibility from the understanding what scientific knowledge was about and the scientific method to obtain knowledge.

Credibility is not the same thing as authority, but this brief history of the vacation of scientist does show how the role of scientists changed and how scientists were regarded by society. Shapin explains that at first science was regarded as a calling, as something divine, and that's where it derived its credibility from. Later science shifted from a calling to a job, a craft, and Shapin argues that scientists then gained their credibility from their knowledge about science and the scientific method. If scientific authority is in decline and the basis on which science gained its authority is no longer seen as legitimate, it could be that this scientific craftsmanship is no longer regarded as something special.

## **2.3 WHAT IS GOING ON WHEN SCIENTIFIC AUTHORITY SEEMS TO BE IN DECLINE?**

This section gives an overview of the range of answers earlier studies provide to the question what might be going on in cases where scientific authority seems to be in decline. The literature discussed in this section does not specifically deal with scientific authority, but focuses mainly on the relation between scientific experts and the public. Defining what aspects play a role in this relation and what the ideal situation should be, also gives insight in what might be going on in cases in which this relation is not ideal, such as when scientific authority seems to be in decline.

### **2.3.1 SCIENTIFIC EXPERTS ARE UNABLE TO SHOW THEY ARE WELL-INTENTIONED**

One explanation for the perceived decline of scientific authority is that the public does not always see the scientific experts as the real expert. Shapin (2004) notes that the public has its own way of deciding who the expert is and does not solely rely on scientific qualifications. Instead the evaluation of expertise is also based on a moral evaluation: who can we trust to do good? In order to trust someone people have to be convinced of the experts' good intentions. An

example is the success of the Atkins diet ('low-carb, high-fat') developed by a cardiologist, who prescribed the opposite of the recommendations of the academic experts ('high-carb, low-fat') (Shapin, 2007). The personal story of Atkins is much more appealing to individuals than the scientific story of the academic experts and therefore people are more likely to listen to Atkins for advice on their diet. The example shows that academic credentials are not enough to be entitled to public authority because it does not guarantee the public that the giver of the advice wants what is best for them, or in other words, has good intentions. What scientists can learn according to Shapin is that in their communication they have to address the concerns that individuals might have, instead of trying to convince people what's best for them by repeating scientific findings. In his work on the discussion about HPV- vaccination, sociologist of science Erwin van Rijswoud (2012) also mentions this practice of repeating scientific findings. After the Dutch Health Council was criticized on their advice about the introduction of the HPV-vaccination, the Health Council reacted by emphasizing the correct and thorough procedures they used to construct the advice and by repeating the statements that were set forth in their report. This reaction did not have the desired effect of silencing the opponents of vaccination.

Good intentions are also related to the ties that scientists have with the industry. When a scientific expert has ties with the industry, this can damage the trustworthiness of the expert, because there is an appearance of conflicting interests. Shapin (2004) states that the commercialization of science is pervasive these days and academia are continually pressed to valorize their research. Shapin argues that scaling back the ties between commerce and academia is not inconceivable; the independence of science has got cash value according to him. Shapin therefore advises to scale back the commercial ties and he also calls for a greater express of outrage among scientists, when commerce corrodes the disinterestedness of their colleagues. In the case of the pharmaceutical industry there also exist commercial ties: vaccine producers fund research by independent scientists in order to obtain independent data and public experts are often, in one way or another, associated with pharmaceutical companies (TROS Radar, 2012). This could play a role when scientific experts are having troubles showing their good intentions.

### **2.3.2 PUBLIC DISAGREEMENT AMONG SCIENTISTS LEADS TO PUBLIC UNREST**

A property of the scientific method is that scientists challenge each other's findings. When scientific findings can survive these disputes and are not falsified during further experiments, the scientific community can reach consensus about them. Shapin (2004) notes that in the political decision-making process it often has to be decided what to do, while the scientists are still disagreeing on the truth of the matter. When political matters concern the public, as with the HPV-vaccination, these natural disagreements become visible for the public, but if the scientific experts are still disagreeing on the truth of the matter, how can the public have a settled view and how can the public decide who the expert is?

Van Rijswoud (2012) observes this phenomenon in the discussion about the HPV-vaccination. After the Dutch Health Council had formulated their advice they were openly criticized by a group of researchers from the Erasmus University. According to Van Rijswoud this attack by fellow scientists fed the public doubt about the usefulness and safety of the HPV-vaccination.

### **2.3.3 SCIENTIFIC EXPERTS LACK TRUSTWORTHINESS IN THE EYES OF THE PUBLIC**

Sociologist of science Brian Wynne (2006) argues that scientific and policy institutions continue to fail to look at their own part in the problem of the public not trusting scientists and policy makers. Wynne notes that although these institutions increasingly involve the public in the discussion, they still tend to think in terms of deficits at the side of the public. Scientists often think the public has a lack of knowledge, a lack of trust or a lack of insight in the process of the scientific method. The bottom line is that scientists often depict the public as not being able to understand or value the findings of scientists, instead of reflecting on their own part in the relation. Wynne (2011) argues that scientists still do not have much trust in the public when it comes to forming an own independent valid meaning of an issue and that scientists overestimate their own ability to create certainty about problematic issues. Scientists seem to deny the limitations that are inherent to scientific knowledge. This attitude contradicts the nuanced combination of enthusiasm and skepticism about certain manifestations of science, which exists among a large part of the public. Therefore Wynne is pessimistic about the future as long as public figures are trying to use scientific authority to justify their decisions. In a way an example of the latter can be found when public experts like Roel Coutinho complain about a decline of authority, after their attempts to calm things down, by denying all uncertainties, have failed.

Instead of thinking of the public as having deficits, Wynne suggests that scientists look at their own role and think about if they are trustworthy in the eyes of the public. Wynne has several ideas about what scientific experts need to change in order to build trustworthiness. Experts have to admit the uncertainties that exist and in addition show how unforeseen impacts are monitored and managed. When it comes to ties with the industry Wynne suggests that scientific experts and policy makers should be honest about the different interests they have and the possible benefits there are for different stakeholders. They have to make the decision-making process transparent.

### **2.3.4 THE PUBLIC IS NOT ABLE TO DEFINE WHO THE REAL EXPERTS ARE**

Sociologists of science Harry Collins and Robert Evans (2002) pose that the public is having difficulties in deciding who the real experts are. They state that there is a difficulty in involving the public in scientific debates that they call the "Problem of Extension": to what extent should the public participate in technical decision-making. Collins and Evans opt for a strict boundary between the knowledge of experts and that of lay-persons, because the public can be wrong and if everyone can be an expert of some sort, how can the public decide who the real expert is? They define several sorts of expertise, such as experienced based expertise and specialized expertise.



Furthermore they suggest that in a scientific discussion a core-set of specialized experts should come to consensus about a certain topic, before the public discussion about the subject can start. With this suggesting they really promote a strict separation between expert and lay knowledge and between a scientific and a political discussion. This way decisions can be made based on scientific knowledge before there is scientific consensus and without the policy makers having to define who the real experts are among all the lay-experts.

An assumption that Collins & Evans make is that scientists have 'special rights' when it comes to esoteric matters. They see that as a part of our culture, as a part of the Western scientific society. If anyone is to deny these special rights of scientists, then that person 'would no longer participate in the Western society as the term is used here'. In section 2.2 we saw that Shapin (2008) showed that the role of scientists in society is changing and that it might well be the case that it's these 'special rights' that are no longer accepted by the public. This being one of the main assumptions of Collins & Evans, the proposed solution of a strict separation between the knowledge of scientific experts and lay knowledge, can be put in doubt.

### **2.3.5 SCIENTIFIC EXPERTS ARE CHALLENGED FOR THEIR CLAIM TO SUPERIOR AUTHORITY**

Te Molder (2011) proposes an interactional perspective of science communication. This perspective focuses on what goals the participants in a debate want to reach, by using certain kinds of expertise. She uses this to show that scientific experts often use scientific certainties expecting that these facts will end the discussion. Te Molder refers to a conversation-analytic study of the way members of focus group talk about experts by Greg Myers (2004). He shows that people who invoke experts are challenged by other participants of the discussion for several reasons, such as being cut off from common experience or for serving their own interests. The opinion of experts is often not open for evaluation and they often think their contribution will close the discussion. Myers argues that it can be useful to see expertise as a claim to the entitlement to speak. According to Te Molder this entitlement to speak, in combination with the assumption that their knowledge will end the discussion, leads to a claim to superior authority. It is this claim to superior authority that is marked my others as controversial, so when the public is challenging scientific experts it could, besides doubting the correctness of the arguments, be resisting the claim of a decisive voice that is not open for evaluation.

### **2.3.6 CITIZENS EXPERIENCE 'A LEAP OF FAITH' IN TRUSTING THE GOVERNMENT**

A different aspect that can play a role in cases where scientific authority seems to be in decline has to with the government. In a qualitative study of organized parental groups that campaign against aspects of vaccination policy, Hobson-West (2007) shows that these groups often do not present themselves as alternative experts who compete with the expertise of the government, but they try to educate parents such that they can make their own choice. Hobson-West argues that in order to actually trust the government, citizens experience they have to take 'a leap of faith'. Anti-vaccination movements even use the blind trust in the government as an argument

for their own cause: they frame the parents who follow the government's advice without hesitating, as being lazy, ignorant and irresponsible.

Sociologist of science Stuart Blume (2006) follows this line of reasoning in a review of empirical data on anti-vaccination groups and the way parents of young children think about vaccination. Blume notes that the way in which the government approaches the public in a vaccination campaign leads to problems, because it differs from other messages that the government sends. Since the 1980s citizens are encouraged to think of themselves as critical consumers and to take responsibility for their own health. This mentality conflicts with the message of the government when they ask parents to follow their advice blindly and get their children vaccinated. This can explain why citizens feel they have to take the earlier mentioned 'leap of faith'. According to Blume the government and scientific experts should acknowledge that citizens have the right and the competence to make a deliberate decision. He argues that people want the right to make an informed choice and in order to do that, the government and scientific experts have to be honest about the risks and uncertainties that exist when it comes to issues like vaccination.

### **2.3.7 SCIENTIFIC EXPERTS IDENTIFY A DECLINE OF AUTHORITY BECAUSE THE SELF-EVIDENCE OF THEIR AUTHORITY SEEMS TO HAVE DISAPPEARED**

The claim that scientific authority is in decline is often made by prominent spokesmen of scientific institutes, such as Roel Coutinho (2010) of the Dutch National Institute for Public Health and the Environment. In the introduction chapter of their book on the disputed authority of science, Dijstelbloem and Hagendijk (2011) do not agree with the diagnosis of a waning authority right away. They think that it is the demise of *self-evident* authority that galls the public experts who declare the decline of authority. The apparent ease with which the opinions of non-scientific participants in the discussion are valued as equal is what these experts object, because they used to rely on self-evident authority that naturally flowed from their status as experts.

At the end of their book Dijstelbloem and Hagendijk (2011) come to the conclusion that there is no need to worry so much about the decline of authority of science as a whole. They argue that citizens have a high opinion of science and that they have high expectations of the outcomes of science. The cases in which authority seems to be in decline are *public* issues in which scientific aspects have to be combined with political aspects in a public discussion. The stakes are often high in these discussions and therefore the appearance of conflicting interest is easily fed. This leads to suspicion among citizens, especially when the public feels they are sidelined by these same experts who seem to have all the power. As a solution to this problem Dijstelbloem and Hagendijk advice to stop exclusively assigning science with the task of defining the problems at hand and the solutions to these problems. This is for instance the case when the Minister of Health asks the Health Council, consisting of only experts, to come with an advice on a topic such as the HPV-vaccination. The next section elaborates further on this idea.

### **2.3.8 IN THE CASE OF THE HPV-VACCINATION SCIENTIFIC EXPERTS PRESENTED THE PROBLEM AS PURELY SCIENTIFIC WHILE OTHER ASPECTS ALSO PLAYED A ROLE**

Philosopher of science Lips (2011) gives an analyses of the discussion about the HPV-vaccination in the Netherlands and his line of reasoning corresponds with that of Dijkstra and Hagendijk. He argues that the criticism on the introduction of the HPV-vaccine was partly caused by the attitude of scientific experts and could therefore not be countered with scientific arguments. According to Lips the problem is that the scientific experts tend to think that in the decision-making process the scientific and the political discussion can be strictly separated. However the problem at hand did not consist solely of scientific characteristics but also contained normative and political aspects. By presenting the problem as purely scientific, other aspects are not visible for the public and this leads to skepticism among the public, who call the advice of the scientific experts into question. Lips uses the case of the HPV-vaccination to give several examples of questions with a normative or political character that the Health Council answered unnoticed: when are scientific findings reliable and applicable? How accurate can a QALY (quality-adjusted life year) be determined and how much is it worth? Are there other relevant problems on which money needs to be spent?

As a solution to this problem Lips uses a suggestion made by Robert Pielke (2007) that scientists become 'honest brokers of policy alternatives'. Instead of letting scientists form a single unambiguous conclusion, they sketch different scenarios in consultation with all the different stakeholders. These scenarios represent the complete spectrum of stakeholders and can be presented to the policy makers, who can make the decision of which scenario to implement.

#### **SENSITIZING CONCEPTS**

The last couple of paragraphs list a total of eight different aspects that could play a role in cases where scientific authority seems to be in decline. During the analysis of the interviews these aspects will be used as *sensitizing concepts*. This term originated with Blumer (1954) and is more recently explained by Bowen (2006). Sensitizing concepts give the researcher a general sense of what to look for in the data, without the clear definitions provided by definite concepts. Practically this means that when analyzing the interview transcripts the researchers keeps his eyes open for signs of sensitizing concepts, without limiting itself to these concepts.

To find out which of the aspects mentioned in this chapter actually play a role in the discussion about the HPV-vaccination, the discussion will be analyzed from the perspective of the stakeholders. The next section formulates the subquestions that have to be answered using the views of the stakeholders, in order to get an idea of what is actually going on.

## 2.4 RESEARCH QUESTIONS

In the introduction chapter of this report two research questions were determined. These questions will be answered by defining subquestions that will be answered by analyzing the view of different stakeholders. Together the results of these subquestions form an answer to the two main questions. Each subquestion is briefly explained.

1. *How do the stakeholders construct the discussion about the HPV-vaccination?*
  - a. *How do the stakeholders define the key issue at stake in the discussion about the HPV-vaccination?*
  - b. *What do the stakeholders construct as the causes of the discussion about the HPV-vaccination?*

It is important to reflect on the term “construct” here. In these research questions “construct” refers to the way in which the stakeholders describe the HPV-discussion during the interview. However, it should be noted that when the respondents are speaking of for instance the causes of the discussion, they are looking back at events in the past. In a way they *reconstruct* what happened, with the knowledge they have now. This will differ from what they would have constructed as causes at the time of the introduction of the vaccine.

a. The literature has made clear there are differences in the views of scientific experts and policy makers and the views of other stakeholders when it comes to what is at stake in a discussion where scientific authority seems to be in decline. For instance scientific experts might be trying to convince the public by hammering on the facts while the public might have trouble in blindly trusting policy makers. Therefore it will be relevant to find out what different stakeholders define as the key issue at stake in the discussion about the HPV-vaccination. Knowing the key issues at stake helps understanding the views of stakeholders and can explain why the discussion became as fierce as it was.

b. The theoretical framework describes several aspects that may have caused the discussion about the HPV-vaccination, such as disagreeing scientists, experts claiming authority or a lack of trustworthiness of the scientific experts. Therefore it will be interesting to find out what the different stakeholders construct as the cause for the discussion. Ideas about the causes of the discussion also have implications for the solutions that can lead to more fruitful discussions in the future.

2. *How do the stakeholders view the role of scientific experts and expertise in the HPV-vaccination case?*

- a. *How do the stakeholders construct the role of science in the discussion about the HPV-vaccination?*
- b. *How do the stakeholders define scientific authority?*
- c. *To what extent do the stakeholders identify a decline of scientific authority in the discussion about the HPV-vaccination?*

a. When it comes to the role of science and scientific experts in the discussion the literature showed that there exist different views on what role science should play in the decision-making process when it comes to topics like the HPV-vaccination. Scientists seem to think they can strictly separate the scientific discussion from the political discussion, but this view is questioned by several authors. It will be insightful to see how the different stakeholders view of the role of science in the discussion.

b. In the previous section it was argued by Dijkstelbloem and Hagendijk (2011) that when public experts complain about a decline of scientific authority, they probably mean that the self-evident authority they used to have is waning, but that the authority of science as a whole not stake. This gives rise to the question what people actually understand by the term scientific authority. If this term is ambiguous, what do people who claim that authority is in decline, try to establish with this claim?

c. In the introduction it was already argued that defining the problem of a decline of scientific authority has consequences for where the solutions to this problem lie; scientific experts could be blaming the public for not listening anymore. Therefore it will be useful to find out who actually defines the problem as such, so it can be analyzed what the consequences are of defining the problem as such.

In the next chapter the method is described that is used for obtaining answers to these research questions.



### **3 METHOD**

This chapter discusses the method that was used to find answers to the research questions. The goal of the research is to gain an insight in a case where scientific authority seems to be in disrepute, by analyzing the views of stakeholders. This chapter explains how and why semi-structured interviews were used, the criteria for the case selection, the selection and recruitment of respondents, the method used for analyzing the data and the limitations of the methods used.

#### **3.1 CASE SELECTION**

There are a couple of reasons to use the HPV-vaccination as the case for this study. In the first place the case contains several aspects that make it into a suitable subject for this study. As mentioned in the introduction the case is often used as an example of the apparent decline of scientific authority, so apparently the people who use it as an example think something is going in this discussion. This also means the perspectives of the stakeholders can be compared with the claims made by those who used the case as an example. Another reason this case is suitable is that the discussion about the HPV-vaccination is an example of a situation in which public experts, whose authority seems to be in decline, face the public. This means there is a situation in which (a lack of) scientific authority could have played a role and therefore it will be possible to investigate this role.

Furthermore there are also some practical reasons to use the HPV-vaccination case. In the first place the case is about a contemporary discussion. This is the third year since the HPV-vaccination was included in the National Vaccination Program and because it is a yearly program most stakeholders are still actively involved in the case. Another advantage of the case being contemporary is that the results of the proposed research can still be of value for stakeholders and thus make a contribution to HPV-vaccination campaigns that are yet to come. A second reason to use the HPV-vaccination is that a wide range of stakeholders can be identified. There are the scientific experts, the government, the pharmaceutical industry, the target public and the media. This makes it possible to explore the different aspects, concerning different stakeholders, explicated in the theoretical framework. A final argument for the selection of the HPV-vaccination case is that a lot of information can be found about the case. Beside websites and a couple of documentaries about the case, it has also been mentioned in earlier studies.

#### **3.2 QUALITATIVE RESEARCH**

This research aims to gain understanding in how the different stakeholders in the discussion about the HPV-vaccination reconstruct the case and the role of science and scientific authority in the discussion. It is important that the method use for the research suits the research question at hand. This study is trying to find out *how* stakeholders construct the discussion about the HPV-

vaccination, so to answer the research question the *subjective* view of stakeholders needs to be captured. As Silverman (2010) explains, a qualitative method would be in place here. Using a quantitative method would result in losing the personal view of stakeholders, by predetermining a range of possible answers, and with that valuable information for the research is lost.

To gain understanding of the views of different stakeholders, these stakeholders need to be interviewed. There are roughly three types of interview methods: structured, semi-structured and unstructured interviews (Bryman, 2008). Structured interviews are particularly suited for quantitative research and are not useful for this study for the reasons mentioned earlier. Semi-structured and unstructured interviews are both suited for qualitative research and with both methods the emphasis is on how the interviewee constructs issues and events. The difference between the two methods lies in the guidance of the interviewer during the interview. In an unstructured interview the interviewer starts with one question and from thereon is free to probe deeper into the subject he or she thinks are useful or being followed up. In semi-structured interviews the interviewer uses an interview guide that contains several questions about topics that need to be addressed during the interview, although the interviewer still has the room to elaborate on other topics that arise during the interview. The research questions of this study show that there are several aspects that need to be discussed during the interviews, such as the causes of the discussion and the role of science, and therefore the method of a semi-structured interview is chosen for this research.

### **3.2.1 SEMI-STRUCTURED INTERVIEW**

Semi-structured interviews involve an interviewer who uses an interview guide to obtain information from a respondent. The interview guide contains questions based on the research questions, but it is not a strict guide in the sense that the interviewer has to stick to it. The guide offers a basis for the interviewer to conduct the interview, but the interviewer is free to deviate from the guide and to elaborate on interesting topics that may rise during the interview.

An interview guide was designed following a method described by Ben Emans (Emans, 2002). This method involves translating the research questions to interview questions by analyzing what information the interviewer needs to answer the specific research question. An example is research question 1a:

*How do the stakeholders define the key issue at stake in the discussion about the HPV-vaccination?*

This questions aims at finding out what the stakeholders describe as the reasons for the introduction of the HPV-vaccine to develop into a discussion. Simply asking respondents what they define as the key issue at stake would probably not result in useful answers because the question is not in an appropriate form to ask in a regular conversation, the formulation is somewhat vague. Instead the interview guide contained the following two questions:



*How did the discussion about the introduction of the HPV-vaccination start, according to you?*

*What do you think was the reason for the unrest among the public?*

The first question is very open and therefore leaves a lot of room for the respondents to focus on what they think started the discussion. In case the answer of the respondent was not yet sufficient according to the interviewer, the second question could be asked to find out what the respondent thinks caused the discussion among the public. This second question also leaves a lot of room for the respondents to freely elaborate on their thoughts.

In this way a basic interview guide was constructed using the research questions. Because every respondent had a unique role in the discussion, questions that could lead to interesting results were specifically constructed for each respondent and added to the interview guide. For instance if respondents had been active in the media, the guide would contain questions about the how and why of these media actions. An example of an interview guide, used during one of the interviews, can be found in Appendix A.

It has to be noted that during the process of analyzing the subquestions of the research questions were modified, because their former formulation did not lead to the results needed to answer the main questions. The interview guide in Appendix A is based on earlier subquestions and does therefore not exactly correspond to the questions as formulated in section 2.4.

In between interviews the interview guide was adapted to the results of earlier conducted interviews. For instance during the first interviews the topic of marketing by the pharmaceutical industry emerged as a topic. Therefore in the interview guides used for the interviews with vaccine producers questions were added about their view on marketing by the pharmaceutical industries.

### **3.3 SELECTION OF RESPONDENTS**

The aim of the research was to interview a wide range of stakeholders such that a wide range of different views on the discussion are included in the research. In order to obtain a list of possible respondents, different groups of stakeholders were defined and it was attempted to plan interviews with at least one respondent of each group. These respondents are not to be thought of as a reflection of the whole group of stakeholders because it is simply not the case that everyone has exactly the same opinion. However, by defining a wide range of stakeholder groups, a lot of different views will be heard and an outline can be made of the different voices that exist in the discussion.

With the selection of a specific individual to represent a stakeholder group it was tried to find an individual that had been involved in the HPV-discussion from the moment the stakeholder group itself became involved. With some stakeholder groups this was relatively easy, such as with the

distressed mothers' website and the NVKP. With larger organizations, such as the vaccine producers, the organizations selected an individual they considered suitable for an interview themselves.

The different stakeholder groups that were defined during the research and with a respondent of which an interview was conducted are:

#### HEALTH COUNCIL

The Health Council was given the task to advise the Minister of Health on the introduction of the HPV-vaccine in the National Vaccination Program. The Health Council gave the advice to include the vaccine in the program, but this advice was criticized by a group of researchers. Because of the role of the Health Council in the introduction of the vaccine a member of the committee of the Health Council that formed on advice on the introduction of the HPV-vaccination has been interviewed for the research.

#### NATIONAL INSTITUTE FOR PUBLIC HEALTH AND ENVIRONMENT (RIVM)

The RIVM had the task to implement the HPV-vaccine in the National Vaccination Program. This meant organizing the rounds of vaccination and communicating with the public about the HPV-vaccination. This task gave the RIVM a central role in the discussion and therefore an interview was arranged with the head of the implementation of the HPV-vaccination.

#### MINISTRY OF HEALTH (MINISTRY OF VWS)

The final responsibility on the introduction of the HPV-vaccine lies with Minister of Health, therefore it was attempted to arrange an interview with the Minister of Health at the time of the advice of the Health Council, Ab Klink. Unfortunately this interview could not be arranged and instead an interview was conducted with the head of the Department of Public Health, Crisis Control and Infection Diseases, at the Ministry of VWS. Because this respondent was not involved in the discussion from the very beginning, a colleague who was involved from the beginning joined the interview.

#### CRITICAL RESEARCHERS

After the advice of the Health Council on the HPV-vaccination, a group of researchers published an article in the Dutch Journal of Medicine in which they questioned the timing of the introduction of the vaccine (de Kok, et al., 2008). This article received a lot of attention in the media and therefore an interview was conducted with one of the authors of the article.

#### SCIENCE JOURNALIST

Leading up to the advice of the Health Council on the HPV-vaccination, a couple of Dutch science journalists paid attention to the discussion, writing in newspapers. These articles contained a critical note and therefore an interview was conducted with one of these journalists.

#### DISTRESSED MOTHERS' WEBSITE

A group that was against the introduction of the HPV-vaccination and that received a lot of attention in the media was the distressed mothers' website. The people behind this website held a fierce campaign against the vaccination and appeared on several television programs. One of the founders of the website became a sort of public figure against the HPV-vaccination.

#### ASSOCIATION OF CRITICAL JABBING (NVKP)

Another group that expressed themselves as opposing the HPV-vaccination and that received a lot of media attention was the NVKP. Although this association usually does not give a negative advice about vaccines, they present themselves as being critical, in this case they did speak out against the vaccination.

#### PHARMACEUTICAL INDUSTRY

The pharmaceutical industry also played a role in the discussion about the HPV-vaccination. They played a role only because they are the producers of the vaccine, but also because they organized a campaign about cervical cancer in the Netherlands and because media pointed to ties with the industries of several members of the Health Council. In the Netherlands there are two producers of the HPV-vaccine: Glaxo Smit Kline and Sanofi-MSD. Interviews were conducted with representatives of both companies.

#### SCIENTIFIC EXPERT (GYNECOLOGIST)

What is still missing in the stakeholders mentioned so far, is a stakeholder that has a positive attitude about the HPV-vaccination, but was not involved in the decision making about the HPV-vaccination or the implementation of it. Therefore an interview with a gynecologist was conducted, who was selected because he appeared in a TV program about the HPV-vaccination and he expressed himself as a proponent of vaccination.

Although interviews with a wide range of stakeholders were conducted, there were also two groups of stakeholders that were thought of to be interesting to interview, but with whom no interview could be arranged:

#### DUTCH SOCIETY OF GENERAL PRACTITIONERS

Besides the article of the Dutch Journal of Medicine there was a second critical paper about the HPV-vaccination, published by the Dutch society of General Practitioners. This article was also mentioned by several respondents so it would have been interesting to include the view of one of their members in the research, but unfortunately they were not willing to participate.

#### DOCUMENTARY MAKER

A television program that is often mentioned in online communities and that was also mentioned by several respondents during the interviews is the episode of Zembla broadcasted

on October 19<sup>th</sup>, 2008. Although the makers of Zembla were contacted to arrange an interview, they unfortunately could not find the time to participate. Also the makers of another television program that broadcasted about the HPV-vaccination, EenVandaag, could not be arranged for an interview.

#### PARENTS IN FAVOR OF VACCINATION

With the inclusion of the representative of the distressed mothers' website the view of a mother against the HPV-vaccination is present in the research. To counter this view it also would have been interesting to include the view of a parent that had expressed enthusiasm about the HPV-vaccination. Following a positive column about the HPV-vaccination in a newspaper a suitable respondent was identified, but an interview could not be arranged.

Appendix B gives an overview of the interviews including date of conducting.

### **3.4 EXECUTION OF INTERVIEWS**

A total of ten interviews were arranged with the stakeholders as described in the previous section. Where possible the interviews were conducted face to face on the location of choice of the respondent. Due to practical reasons the interview with representatives of the distressed mothers' website and of the NVKP were held using Skype. Both the interviewer and the respondents did not experience the fact of not being face to face as hindering for the quality of the communication. Although it can never be ruled out that a face to face interview would have resulted in slightly different results.

When contacting the respondents a short description of the research was given, bearing in mind not to give away too much information. Most respondents found this short description enough information for agreeing to participate in the research. Only the respondent of the Ministry of VWS requested information about the general questions of the interview, such that she could prepare herself for the interview. The reason behind this was that the respondent did not yet occupy her function at the time of the introduction of the vaccine. This was also the reason that she invited an employee of her department who did work at the time of the introduction, to join the interview. Although the respondent was not involved at the case at the time of the introduction of the vaccine, the interview is still included in the research. The reason for this is that the respondent was able to give insight in the way the Ministry of VWS approached the discussion and where necessary the employee of her department could correct her.

The interviews lasted from 45 minutes up to 70 minutes and were recorded such that they could be transcribed afterwards. The analysis of the interviews is described in the next section

### 3.5 ANALYSIS

All interviews were transcribed verbatim and entered in Atlas.ti software. After transcription the interviews were analyzed for passages that formed answers to the research questions. These passages were coded according to the research question that they answered. This way an overview could be generated of all the different answers each of the research questions. These overviews were then analyzed for answers that indicated a similar point of view and which together could form a distinctive answer to the research question. During the analysis the sensitizing concepts, as described at the end of section 2.3, were kept in mind. This resulted for instance in section 4.2.1 about disagreement among scientists, which follows the concept of section 2.3.2.

The difficulty in this analysis was in finding the overarching themes that can be found in the answers of the respondents. At first the interviews were analyzed too literally instead of looking at the way in which respondents described the discussion. It is important to understand that the answers of the respondents can't be used as facts, because with interviews you have to do with subjective descriptions of reality. The information relevant for this research lies in the way in which the respondents construct this reality.

To give an example of the way the interviews were analyzed, the analysis of answers to research question 1b (*What do the stakeholders construct as the causes of the discussion about the HPV-vaccination?*) is described here. At first the interview transcripts are searched for all causes of the discussion that are mentioned by the respondents and each interview fragment containing a statement about a possible cause is coded. Once this task is completed the remaining fragments are categorized according to the stakeholders involved with the causes mentioned, such as the government, scientists or the industry. Each group is then analyzed for similarities and this way for instance the finding emerged that several respondents point to the push of the industry as a cause for the unrest among the public, as presented in section 4.2.5.

The results of this analysis are presented in the next chapter. Each research question is treated in a separate section and each different answer to a research question is discussed in a separate subsection. To show how the results were obtained, fragments of the interviews that illustrate the findings are inserted. Because it is interesting to know which respondent is responsible for an interview fragment, for instance it makes a difference knowing if something is said by a representative of the government or by a member of an anti-vaccination group, the respondents are coded according to the table presented below.

| <b>Code</b> | <b>Respondent</b>   |
|-------------|---|
| <b>CrRe</b> | Critical researcher   |
| <b>HeCo</b> | Member of Health Council  |
| <b>ScJo</b> | Science journalist  |
| <b>DiMo</b> | Representative of the Distressed mothers website                                  |
| <b>NVKP</b> | Representative of Association of Critical Jabbing (NVKP)                          |
| <b>RIVM</b> | Representative of the National Institute for Public Health and Environment (RIVM) |
| <b>VWS1</b> | Representative of Ministry of Health (VWS)  |
| <b>VWS2</b> | Representative of Ministry of Health (present at same interview as VWS1)          |
| <b>Pha1</b> | Pharmaceutical industry 1   |
| <b>Pha2</b> | Pharmaceutical industry 2   |
| <b>Gyne</b> | Oncological Gynecologist  |
| <b>I</b>    | Interviewer   |

### 3.6 LIMITATIONS

The method used for this research has several limitations. In the first place the data collection is very much dependant on the skills of the interviewer. Considering the fact that the interviewer had no previous experience with doing qualitative research, this will have resulted in not getting all interesting information from the respondents and in making more mistakes during the interview than an experienced interviewer would have.

There are several pitfalls that the interviewer has to avoid (Emans, 2002). The most common problem with interviews is asking leading questions, which can result in the respondent giving answers he normally would not give. To give the reader the chance to decide how much influence the interviewer had on the answers of the respondents, the fragments that are used in the analysis contain both questions and answers. Other common problems are a failure to listen closely which can lead to missed opportunities to obtain interesting information, and a failure to probe when necessary, such that during the analysis it is not entirely clear what a respondent meant with a specific answer. These last two problems do not become apparent until analyzing the interviews and at that point it is no longer possible to correct the mistakes.

Another limitation is that the data was only analyzed by one person. This may have led to a colored view in the presentation of the results and it could be possible that the researcher missed certain aspects that are present in the interviews. In other words it could well be

possible that a different researcher comes to slightly different results after analyzing the interviews.

Looking at the respondents interviewed for this research there are also some limitations. Only one representative was interviewed of each stakeholder group and it is possible that a different representative would have led to differing answers and thus to different results. In addition only ten respondents were interviewed, if more respondents were interviewed this could have led to different aspects emerging during the analysis.

Another limitation as a result of the respondents used for this research, lies in the stakeholders that were *not* interviewed. A large part of the population did follow the advice of the RIVM and got vaccinated. The voice of this group is not present in the research and therefore the research is focused on the stakeholders that actively participated in the discussion. This could have resulted in a somewhat predominant negative view about the vaccine and the communication about the vaccine, as expressed by the anti-vaccination movements.





## 4 **RESULTS**

This chapter gives an overview of the results of the analysis of the conducted interviews. The results are presented according to the research questions as presented in Chapter 2:

1. *How do the stakeholders construct the discussion about the HPV-vaccination?*
  - a. *How do the stakeholders define the key issue at stake in the discussion about the HPV-vaccination?*
  - b. *What do the stakeholders construct as the causes of the discussion about the HPV-vaccination?*
2. *How do the stakeholders view the role of scientific experts and expertise in the HPV-vaccination case?*
  - a. *How do the stakeholders construct the role of science in the discussion about the HPV-vaccination?*
  - b. *How do the stakeholders define scientific authority?*
  - c. *To what extent do the stakeholders identify a decline of scientific authority in the discussion about the HPV-vaccination?*

The following sections each cover one subquestion and describe the answers that were distinguished during analysis of the interviews. Fragments of the interviews are quoted to illustrate and clarify the patterns found in the interviewees' responses, which are described in each paragraph. All fragments have been translated as literal as possible from Dutch to English, by the author of this report. The original Dutch versions of the fragments can be found in Appendix C. Irrelevant parts of fragments are replaced with a dotted line between brackets. Several fragments are dependent on the context of the fragment and in that case clarifying information is added between brackets. Because it is interesting to know which respondent is responsible for an interview fragment, it makes a difference knowing if something is said by a representative of the government or by a member of an anti-vaccination group, the respondents are coded according to the table presented in Chapter 3.

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## 4.1 HOW DO THE STAKEHOLDERS DEFINE THE KEY ISSUE AT STAKE IN THE DISCUSSION ABOUT THE HPV-VACCINATION?

This section focuses on subquestion 1a “*How do stakeholders define the key issue at stake in the discussion about the HPV-vaccination?*” During the interviews the respondents mentioned several different aspects that they thought had played a role in the discussion about the HPV-vaccination. These aspects ranged from the side effects of the vaccine to cervical cancer being an emotional subject, and from one-sided media coverage to the industry pushing for a quick introduction of the vaccine. Some of these aspects are described in section 4.2, where the possible causes of the discussion are analyzed, and instead of listing all these aspects here, I will describe the general patterns of the context in which the more specific aspects were mentioned.

### 4.1.1 STAKEHOLDERS DEFINE THE KEY ISSUE AS A NON-SCIENTIFIC PUBLIC DISCUSSION THAT FOLLOWED THE SCIENTIFIC DISCUSSION

The first thing that stands out when analyzing the interviews is that, in their description of the discussion, several respondents make a clear distinction between a *scientific* discussion and a *public* discussion. This distinction is made by stakeholders who were already involved in the discussion at the time when the Minister still had to make a decision about the introduction of the vaccine, such as the critical researcher, the science journalist and the vaccine producers. One of the vaccine producers expresses the distinction very clearly:

|    |              |  |
|----|--------------|--|
| 1) | <b>I:</b>    | How did the discussion about the introduction of the HPV-vaccination come about, according to you?   |
|    | <b>Pha1:</b> | [...] Are you speaking of the discussion <i>before</i> the introduction, or the discussion <i>after</i> the introduction. You're speaking of "about" the introduction.   |
|    | <b>I:</b>    | Yes, what's the first thing you think of?  |
|    | <b>Pha1:</b> | Well, there have been two discussions, there have been several.  |
|    | <b>I:</b>    | Ok, you can name them both.  |
|    | <b>Pha1:</b> | Well, in the first instance I think, before the introduction, there were a couple of researchers who thought the information, scientific knowledge, which was collected, to come to a decision [...] was insufficient and they felt the need to investigate this themselves [...] That was the first discussion. That discussion then transferred, from scientists to people who are more members of the general public. |

The point where, according to this respondent, the scientific discussion ends and the public discussion starts seems to be the decision of the Minister on the introduction of the vaccine, as the science journalist points out in the next fragment.

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| 2) | <b>I:</b> | At a certain moment the discussion became much bigger, due to a lot of different circumstances. |
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|--------------|---|
| <b>ScJo:</b> | Yes.  |
| <b>I:</b>    | What was the discussion about at that moment, do you think? At a certain moment the advice had been given, by the Health Council, the Minister decided to introduce the vaccine and then a discussion erupted, which involved a lot of people.                          |
| <b>ScJo:</b> | Yes, but the discussion already simmered much longer. Look, in fact the decision of the Minister to introduce the vaccine on the authority of the Health Council was [...] the end of the discussion. Then, well, then the scientific discussion was more or less over. |

The respondents who make the distinction between a scientific and a public discussion define two differences. First of all, they define the scientific discussion as being based on science and scientific facts; as a result they implicitly define the public discussion as non-scientific. Secondly, the participants of the two discussions are different: the scientific discussion was held among experts and decision makers. It seems to be important for these respondents to make clear that they act in a discussion based on science and not on emotions. The vaccine producer in the next fragment illustrates the differences and he even speaks of the scientific discussion as the “real discussion” and states that the public discussion is based on opinions and with that he implicitly constructs opinions as not being based on facts.

|              |  |
|--------------|--|
| 3) <b>I:</b> | What role did scientific information play in the discussion, according to you?   |
| <b>Pha2:</b> | Well, in the public discussion too little. Too little. In the real discussion so to speak, among those who, well, decide, among the Health Council and the RIVM, a lot. I think that, they really based themselves on sheer facts. And the public debate was about opinions that were not, not really supported by facts. That was about opinions of people, which were held against each other and not about the facts. [...] so the debate, so to speak, in the public media, was different from the debate among the experts [...]. |

By making a distinction between a scientific and a public discussion, the respondents place themselves outside this public discussion and they seem to degrade the public discussion as not to be taken seriously. Even the critical researcher, whose article was used by anti-vaccination movements to support their cause during the public discussion, distances herself from this public discussion.

|              |  |
|--------------|--|
| 4) <b>I:</b> | What role did scientists play after the advice had been given? Did they still interfere with the discussion then?  |
| <b>CrRe:</b> | Well, at that moment I really had the feeling like, well, it has been introduced, so it finished now. That, then I'm not going to make a row of it anymore, it's a fact now, well, then we shouldn't put it up for discussion anymore. [...] I just wanted to make that voice heard once, that opposing force, and then, that was my goal. That for once, the other side of the story would be heard and [...] people kept coming with, "do you want to appear in this or that magazine" and after a while I felt like, now I'm done with it, you know. The discussion is over, it has been introduced and now we should make the best of it and just hope that we weren't right after all, that, yes. |

This last fragment also shows that according to this respondent the subject of the scientific discussion was whether or not to include the HPV-vaccine in the National Vaccination Program; this corresponds with the earlier statements that the decision of the Minister to include the vaccine in the program formed the end of the discussion.

So the respondents who make a distinction between a scientific and a public discussion seem to distance themselves from that public discussion and position themselves as a participant in the scientific discussion.

#### 4.1.2 THE STAKEHOLDERS THAT DISTINGUISH A SCIENTIFIC AND A PUBLIC DISCUSSION

##### CONSTRUCT THE KEY ISSUE IN THE SCIENTIFIC DISCUSSION AS A CONFLICT OF VALUES

The discussion that was framed as a scientific discussion in the previous section was a discussion about whether or not to include the HPV-vaccine in the National Vaccination Program. By labeling this discussion as scientific, one would expect that it revolved around the interpretation of research results and the scientific evidence for the efficacy of the vaccine. This conception is partly confirmed by several respondents, but not everyone views this as the main point of discussion in the Health Council, which at that time had to form an advice on the introduction of the vaccine. Several respondents speak of a more political discussion on the interpretation of research results. There seemed to have been two camps: screeners and epidemiologists on one side, and virologists and vaccinologists on the other side.

The science journalist, who already followed the discussion at the time that the Health Council was asked to form an advice, explains what he thinks was going on in the Health Council.

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| 5) | <b>I:</b>    | And why, do you think, that despite those uncertainties [about the efficacy and side-effects of the vaccine], the advice has been given to do it anyway?  |
|    | <b>ScJo:</b> | That I don't know. I mean, that is in the hands of the Health Council. [...] The problem is, there are screeners and there are virologists. Screeners say, so much effort for just a single prevented death, is that worth all the effort. And then there are virologists and vaccinologists, like Roel Coutinho [director of the Centre for Infectious Disease Control at the RIVM], who say, yes, but there is a vaccine that can prevent <i>cancer</i> , isn't that wonderful, shouldn't we introduce that? So they are enthusiastic in a very different way. And I think that camp has won within the Health Council. |

As the science journalist points out, he believes there was not so much disagreement about the scientific research on the vaccine, but there seemed to have been disagreement about what to do with the results: both sides seemed to agree that the vaccine could possibly save lives, but they valued this differently. This difference is confirmed by both the member of the Health Council as well as the critical researcher, who both describe the situation slightly different.

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| 6) | <b>I:</b>    | And what, what is the main point of discussion? Or isn't that public?   |
|    | <b>HeCo:</b> | Actually it's all those points [that are mentioned in the Health Council report]. And look, if you, and I think that's one of the things that those epidemiologists |

stumbled at, if you look from an Oncological point of view at the health problem, then 250 deaths per year, well, that's not something a lot of people are worried about. But if you look at it from, for example, the point of view of vaccination experts, they say that if you can prevent 100 deaths per year with a nice preventive remedy at a young age, then that's a very big success. Because with the measles vaccination we also prevent, maybe 30 deaths per year or 10 deaths per year.

The member of the Health Council confirms that the possibility of saving lives was an important issue within the Health Council. She also states that according to the screeners and epidemiologists the number of lives that could possibly be saved was not very impressive. The first statement is confirmed by the critical researcher, but she does not agree on the second statement, as the next two fragments show.

- 7) **I:** Why had the advice been given anyway, do you think? [...]
- CrRe:** I know that there was a discussion back then, the chairman of the Health Council, he thought that, those 200 deaths, or those 100 deaths per year, that you would gain, that, he said: "who are we to say that you cannot introduce that, for those 100 women". And well, of course they were the institution that could say that exactly [...].

Here the critical researcher agrees with the science journalist on the statement that it was the possibility to save lives that was decisive within the Health Council. However, contradicting the statement of the member of the Health Council, the critical researcher does agree that those lives are important, but she thinks there is another way to reach the same result, in the form of an improved screening program, which could be cheaper and less risky than vaccination.

- 8) **I:** So you have the idea that the Health Council, they really wanted to chose between a "yes" or a "no" and not-
- CrRe:** Yes, well, they thought those 100 deaths, that weighed heavily for them. It's true of course, but they didn't know what the downside was. If you [think] of negative and high costs, well. You could have said, we're not doing it and we're going to make sure that more people show up for the public screening and then you also might have saved those 100 deaths.

Summarizing, it could be said that the respondents describe the discussion about the introduction not so much as a purely scientific discussion, but more as a value conflict about whether or not to introduce the vaccine. This is very interesting in the light of the previous section, because here the public discussion was dismissed as being non-scientific, but as it turns out the scientific discussion itself is also not framed as purely scientific either, but more as a conflict of values.

An interesting aspect of the last two sections is that people seem to define a discussion in different ways, according to what they want to achieve with that definition. By defining the discussion as scientific they can exclude lay people, such as anti-vaccination movements, from the discussion. However when the scientific input seems to be ambiguous they can define that

same scientific discussion as a conflict of values in order to support their own cause in the discussion.

So the stakeholders that were involved in the discussion that was described as scientific construct this discussion as a value conflict. The next section discusses how the stakeholders that are involved in the discussion that is described as public define the key issue at stake.

#### 4.1.3 STAKEHOLDERS AGAINST HPV-VACCINATION CONSTRUCT THE KEY ISSUE AS STANDING UP AGAINST THE ONE SIDED STORY OF POLICY MAKERS

The scientific experts define the discussion as a scientific discussion based on scientific information followed by public discussion that was non-scientific. However, the respondents who are against the HPV-vaccination, the representative of the distressed mothers' website and the representative of the Association of Critical Jabbing (NVKP), have a different view. The representative of the distressed mothers' website explains how she thinks the discussion started.

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| 9) | <b>I:</b>    | How did the discussion about the introduction of the HPV-vaccination come about, according to you?   |
|    | <b>DiMo:</b> | Well, it came about because we, the other side, those who think differently, came out with it. I'll tell you how I started, that might be interesting. In 2008, then, well, then there appeared in the media, headlines in the newspaper, fragments on television, you know, in the summer and fall, that that vaccine was about to come, in fact it was being promoted. And every time I saw that, then my thoughts were, my feeling was, this can't be true. Next thing you know we're getting vaccinated against stomach cancer, against liver cancer, or we're getting a cocktail. |

Two things stand out in this fragment. First of all, the respondent defines the media attention for the HPV-vaccination as the reason to get suspicious about the vaccine and she defines her own actions, coming out with what she later describes as "the other side" of the story, as the start of the discussion. This means that for her the decision of the Health Council falls outside the scope of the discussion and she does not distinguish two separate discussions. The second thing that stands out is that she describes herself as someone who "thinks different". She explains this in a later fragment.

|     |              |   |
|-----|--------------|---|
| 10) | <b>I:</b>    | At the start you said... You described yourself as "thinking differently".  |
|     | <b>DiMo:</b> | Look , the RIVM and other members of the government and the lab technicians, virologists, and what not, they are of course firmly convinced... or they are saying it out of "obligations", because well, if they're convinced deep within remains the question. But anyway, they all promote it strongly; we are the ones that say, hey, wake up; there is also a different side. |

This fragment makes clear that the respondent see herself as someone who stands up against an established order that is in favor of vaccination. With that she defines the key issue as a conflict

between the policy makers, “the RIVM and other members of the government”, and the people who think different about vaccination.

The representative of the NVKP does not describe his association as thinking differently, but he does define the key issue of the discussion in a similar way as the representative of the distressed mothers’ website, opposing the message of the government.

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|-----|--------------|---|
| 11) | <b>I:</b>    | Ok, well, so if I understand it correctly the information [that doubts the usefulness of the vaccine] that you provided is...   |
|     | <b>NVKP:</b> | ...correct and right!   |
|     | <b>I:</b>    | Yes, exactly. But the advice has been given by the Health Council anyway.   |
|     | <b>NVKP:</b> | Yes, ridiculous, isn't it? It's just unbelievable! [...] The title of the advice is "Vaccination against cervical cancer". In my opinion that's the first blunder the Health Council commits. Because it's not a vaccination against cervical cancer at all. Again it's a way of influencing people who know nothing about the subject. It is a vaccination against an HPV-infection, which, in very exceptional cases, could form a trigger for cervical cancer. We have to wait and see about that, they think that's the way it is, but in any case it's not a vaccination against cervical cancer. Well, it's these kinds of things that we object. The one-sided, positive, unfunded, propaganda for such a vaccine. |

The respondent is clearly disagreeing with the way the government communicates about the HPV-vaccine. He sees it as the goal of his association to object to what he describes as pro-vaccination propaganda by the government and he wants to show the other side of the one-sided story of the government.

In the previous section several respondents made a distinction between a scientific and a public discussion. The representative of the NVKP does not identify this distinction, but he does identify a moment in time when the public discussion started to grow, as the next fragments show.

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|-----|--------------|---|
| 12) | <b>I:</b>    | Where do you place it in time? That you started with it [HPV-file]?   |
|     | <b>NVKP:</b> | It must have been in 2007, 2008? Thereabouts.   |
|     | <b>I:</b>    | Yeah, ok, so even before the Health Council came with an advice.  |
|     | <b>NVKP:</b> | Yes, because, when we had finished that report, and had submitted it, then it formed a reason for the Health Council, to invite us to discuss it. And that is still visible, because in the final report that the Health Council delivered to the Minister, we're mentioned. Well, that has been the start of something that became bigger and bigger in the end. [...] |

The fragment makes clear the association was already active on the topic of HPV-vaccination before the Health Council gave their advice to the Minister. And instead of framing the decision of the Minister as the end of a scientific discussion, the respondent sees their participation in the advice of the Health Council as the start of something bigger, but he does not specify this “something” in this fragment. Later on during the interview the respondents somewhat clarifies what he means.



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| 13) | <p><b>NVKP:</b> Normally it's the case that we provide the information, so parents, most of the time they're parents, can make the decision: do I get the vaccine, don't I get the vaccine. We don't provide an advice. With the HPV-vaccination we did give an advice, for the first time, we said, girls, you shouldn't do this. Well, and, that was included in the dossier, and other people copied the story and that became bigger and bigger and, well, at a certain moment it became a nation-wide discussion so to speak.</p> |
|-----|--|

It seems that the respondent is talking about the discussion about the HPV-vaccination when he is talking about “something” in fragment #12, because he states that the end result was a nationwide discussion about the HPV-vaccination. In a way he defines the same public discussion as was done by other stakeholders, only he does not make a distinction between a science based discussion and a public discussion, he just sees the discussion getting bigger.

#### 4.1.4 REPRESENTATIVES OF THE GOVERNMENT DEFINE THE KEY ISSUE AS A COMMUNICATION PROBLEM BETWEEN THEMSELVES AND THE PUBLIC

A final definition of the key issue at stake comes from the stakeholders that are responsible for the implementation of the HPV-vaccine in the National Vaccination Program: the Ministry of Health (VWS) and the National Institute for Public Health and Environment (RIVM). They are neither on the side of the scientific experts who make a distinction between two discussions, nor are they on the side of anti-vaccination groups. Instead they see the discussion as a collection of obstacles in their attempt to reach the audience to which they want to get their message across.

This view is not surprising since it is the task of the ministry and the RIVM to inform the public about the HPV-vaccine. The representative of the RIVM sees it as a part of her job to respond to all messages in the media.

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| 14) | <p><b>I:</b> Do you blame them [journalists] for that [magnifying negative information]?</p> <p><b>RIVM:</b> Yes, that's writing headlines. A journalist can be as nuanced as he wants, but that can... Of course this has big effects, I mean, I, well, I think people [have] a responsibility in what they [write] down... I am under no illusion that you can control that, thereafter it's our task to respond, to all those sounds. I can blame ourselves that at first we didn't succeed in that task.</p> |
|-----|--|

The respondent addresses what she considers as her responsibility: refuting negative messages in the media, so she defines these negative messages as a threat to the image she wants the public to have of the HPV-vaccine. And instead of just blaming the media for frustrating the government campaign, she sees it also as the failure of the RIVM that they did not respond well enough to the negative messages in the media. With that she defines the key issue in the discussion not so much as debating with the movements that cause negative media coverage, but as dealing with the problems that these movements cause for the communication. As a result the respondent does not frame the discussion as a struggle to win the discussion about who is wrong and who is right, but she is able to look at how she can improve her own campaign in order to get the desired message across.

The respondents from VWS also describe the discussion in terms of communication problems. In the next fragment one of the respondents tries to explain what the goal is of government communication when it comes to the National Vaccination Program.

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| 15) | <b>I:</b>    | And what goal do you want to achieve with such an interview [of a government representative in the media]?   |
|     | <b>VWS1:</b> | That's a good one, we just talked about that [...] And that's a point that we're discussing at the moment, the goal of our strategy is providing information about measures citizens can adopt, and which you provide as government, as protection for infectious diseases. [...] And I think, and then we arrive at another question, I think, looking back, that we didn't communicate explicitly about what that goal of our message exactly was, it was primarily like: it's good for you. |

By defining a problem in the government communication, the respondent takes responsibility for a part of the discussion. When the interview continues she explains what she thinks the effect was of not explicitly considering the goal of their campaign.

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| 16) | <b>I:</b>    | And what kind of effect did that have, do you think?  |
|     | <b>VWS1:</b> | Well, I think that many things are interrelated. Like Philip [respondent VWS2] said earlier, it's a distinct vaccine, for a distinct age group, a difficult age group, and on top of that there are possible effects in the long run. And on top of that it's related to sexual behavior. So it was a very distinct setting, but in addition I think [...] the government on the one hand did exude: you have to make the decision, but you're stupid if you make the decision not to get your child vaccinated. While in the second round the message was more like, gosh, we want to offer it, for those who want it, and we want to make all the information available. So that's a slightly different tone. |

The respondent lists a couple of aspects that caused difficulties in the communication. It is interesting to see that these aspects are all properties of the vaccine itself or properties of the target public, so in this case she does not blame the other stakeholders in the discussion, but she identifies communication difficulties specific for this vaccine. It does not become clear how and if the respondent knows that these aspects actually played a role in the failing of the campaign. By stating that the message of the government came across as if "parents were stupid if they chose not to get their children vaccinated", she does acknowledge some of the critique of anti-vaccination movements, who felt they had to stand up the government because they felt the government propagandized the vaccine.

## 4.2 WHAT DO STAKEHOLDERS CONSTRUCT AS THE CAUSES OF THE DISCUSSION ABOUT THE HPV-VACCINATION?

This section presents the answers given by respondents on the subquestion "*What do the stakeholders construct as the causes of the discussion about the HPV-vaccination?*", so this section discusses what the different stakeholders think were the main reasons for the introduction of the HPV-vaccination to become a discussion, instead of passing without much notice.

#### 4.2.1 PARTICIPANTS IN THE SCIENTIFIC DISCUSSION CONSTRUCT PUBLIC DISAGREEMENT AMONG EXPERTS AS THE CAUSE FOR THE PUBLIC DISCUSSION

In section 4.1.1 we saw that some of the respondents define a scientific discussion that was followed by a public discussion. This does not mean that these respondents see these discussions as unrelated; in fact they identify the political discussion within the Health Council as one of the causes of the public discussion.

As we know, in March 2008, the Health Council gave a positive advice on the introduction of the HPV-vaccine in the National Vaccination Program, but this did not mean the discussion was closed for all scientists. The critical researcher, together with some of her colleagues, published an article in the Dutch Journal of Medicine because they wanted to show the public the other side of the, in their eyes, too positive story of the Health Council.

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| 17) | <b>I:</b>    | How did you get involved with the discussion yourself?  |
|     | <b>CrRe:</b> | [...] With a group we wrote an article in the Netherlands Journal of Medicine, because we were questioning whether the time was right to already introduce it, for the whole population. And especially because at time we had the feeling there were only positive sounds and we knew for certain that within the Health Council there were also negative sounds, but to the outside only the general approval was shown. So we were of the opinion that it should be nuanced and for once also [should show] the other side of the story, which was known. Among experts that was known, but with that group we were of the opinion that it could also be filtered to the general population. |

This article plays an important role in the perception of the public discussion of several stakeholders that are in favor of vaccination, such as the representative of the RIVM, a producer of the vaccine and the member of the Health Council. They see this article as partly responsible for the public discussion, as the next fragments show.

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| 18) | <b>I:</b>    | Can you describe how the discussion about the HPV-vaccination came about, according to you?   |
|     | <b>RIVM:</b> | [...] The article in the Journal of Medicine [...] in which they [the critical researchers] gave their opinion on this HPV-vaccination, obviously played a major role. They said: it's too early for that vaccination; it's not an urgent public health issue. [...] The message that these people, who had already shared their vision within the Health Council, and which they then published, somewhat went to lead a life of its own, because then people said: even the experts think it's too early. That played a part. |
|     | <b>I:</b>    | Do you blame them for that?   |
|     | <b>RIVM:</b> | I'm of the opinion that they should have been more cautious. [...] It did have a major impact, if you then hear everyone say: so you see, it's not at all just a hype or a conspiracy theory, or whatsoever, no, even scientists are of the opinion that we shouldn't do it. I think that played a major role.  |

The representative of the RIVM states that article of the critical researchers was used as an indicator that the public discussion was more than just a hype or a conspiracy. Implicitly she

says that scientists still have authority among the public, because she uses the fact that the authors of the article are scientists to explain the impact that she thinks the article had on the public.

One of the vaccine producers explains what he thinks is the problem with researchers criticizing each other in public.

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| 19) | <b>I:</b>    | So if they [the critical researchers] had performed it [the research on the efficacy of the vaccine] themselves, then they would have interpreted it [the results] more positive?   |
|     | <b>Pha1:</b> | Yes, because what they did now [...] [is] asking a lot of questions, something a researcher is legitimized to do, but when you as a researcher are engaging in the public media and you're asking questions that you would ask, well, among researchers, among each other, then those, in themselves correct questions, have a completely different effect.   |
|     | <b>I:</b>    | Yes, being...?  |
|     | <b>Pha1:</b> | Yes, being, [...] a journalist doesn't have the time to write that down in an appealing way, accessible for lay people, so he makes it a bit more compact and shorter and makes it more catching, by magnifying in particular the question marks that could possibly exist, could possibly exist. Ehm, well and then it will escalate, because, well, in fact a journalist emphasizes, most of the time, to be assured of attention for his article, precisely the negative aspects. Those are the first to be emphasized. And in a way that's a shame, because then unrest arises [...]. |

The producer of the vaccine thinks scientists in general should be careful with criticizing each other publicly, because he thinks that media will often emphasize the negative aspects and that is what he thinks causes public unrest. The producer of the vaccine also links the article to a lack in government communication on the internet. He is not the only respondent who points at a failing government communication. This is discussed in a later section.

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|-----|--------------|---|
| 20) | <b>I:</b>    | How did the discussion about the introduction of the HPV-vaccination come about, according to you?  |
|     |              | [...]   |
|     | <b>HeCo:</b> | Then [when the Minister decided on the introduction of the vaccine] two things happened. In the first place there was a group of epidemiologists who wrote an article in the Netherlands Journal of Medicine, in which they not so much doubted the effect of the vaccine, as well as [asked] the question if this was the right moment to introduce it already. That has been picked up by the media as, look, these scientists do not agree with each other at all. |

The member of the Health Council also frames the article of the critical researcher as one of the causes of the discussion because it was picked up by the media. This last fragment confirms the findings of section 4.1.2 that the member of the Health Council thinks that the discussion within the Health Council was not so much scientific, for instance about the efficacy of the vaccine, but was about what to do with the scientific results.

It is notable that none of the respondents criticize the content of the article, but the researchers are blamed just for the fact that they wrote the article. This is remarkable because you would expect scientists to debate over scientific results, but in this case an article is criticized for being written at all.

The two respondents from organizations that in the case of HPV-vaccination could be labeled as anti-vaccination, i.e. the representative of the distressed mothers website and the representative of the NVKP, do not construct this public disagreement among scientist as a cause of the discussion. This is remarkable, since this is the opposite of what the respondents earlier this section stated. However the representative of the NVKP does agree with the statement that the message of a scientific expert has more impact than that of an average citizen.

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| 21) | <b>I:</b>    | Yes, and so the reason that you doubt the correctness of the advice is also based on scientific research, or the lack of it.   |
|     | <b>NVKP:</b> | Yes, and the doubt about the advice of the Health Council, I think, is extremely well formulated, by those four epidemiologists, in that Netherlands Journal of Medicine. [...] Especially Coutinho [of the RIVM] who declared "Yes, isn't it outrageous, that in this stadium scientists, are opposing government decisions, and this kind of discussions shouldn't take place publicly", well, and so on, and all such nonsense. Because that's what has caused enormous damage, right. So, look, if the NVKP shouts something, they let that pass. But so if four scientists, who can count ánd cancer ánd the interpretation of figures to their knowledge and expertise, if they draw the conclusion that the Health Council drew the wrong conclusion, on five out of seven criteria, yes, then the public starts to think, well, perhaps it's all not quite as presented. |

The respondent acknowledges the role that the article had, mainly because the RIVM fiercely responded to it. He constructs the opinion of the RIVM as if they were angry with the critical researchers for causing a public discussion. He clearly disagrees with this and this confirms the finding, of section 4.1.3, that he wants to take part in a scientific discussion of which he thinks the government is trying to prevent. He is confirmed in this view by the fierce reaction of the RIVM. The respondent also focuses on the content of the article, because it supports his own point of view. But as the cause for the discussion he constructs his own dossier and that of the distressed mothers' website, because as we will see in the next section the anti-vaccination movements mainly focus on their own role in the discussion.

Several stakeholders constructed scientists who openly disagree as being fodder for anti-vaccination movements. What stands out is that the anti-vaccination movements do not point to disagreeing scientists as a cause for the discussion, but the respondent NVKP does recognize that the RIVM seemed to think so. What also stands out is that the scientists who are disagreeing are not so much criticized for the content of their message as they are for just the fact of openly disagreeing.

#### 4.2.2 STAKEHOLDERS AGAINST VACCINATION CONSTRUCT THEIR OWN CAMPAIGN AS THE START OF THE PUBLIC UNREST

Looking back at fragment #9, it is clear that the representative of the distressed mothers' website sees her own actions as the beginning of the discussion about the HPV-vaccination (*"Well, it [the discussion] came about because we, the other side, those who think differently, came out with it"*). She is encouraged in this idea by actions of the government, who on one occasion invited her to discuss the situation.

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| 22) | <b>I:</b>    | You mentioned Minister Klink earlier. Did you have contact with the government in one way or another?  |
|     | <b>DiMo:</b> | RIVM. Roel Coutinho. [...] We were invited, during the summer of 2010, as a result of the HPV-campaign. The question was actually, how is it yet possible that a mother can mess the whole thing up? That was the real question.   |
|     | <b>I:</b>    | Yes, so you, so you had the feeling that they spoke with you to... improve their own campaign so to speak.   |
|     | <b>DiMo:</b> | And not just with me, but also with, ehm, others, who oppose and who provide information, so there were more of us. And yes, it was indeed to find out, how can we improve everything. Because, what the government never had expected, was that a mother could get simple thoughts, about the HPV-vaccine maybe not being so safe. And that she could mess the whole thing up using the internet. <i>{laughing}</i> Wasn't that a miscalculation. |

The respondent not only states that the government sees her as the cause of the unrest, but she also makes clear what she thinks of how the government looks at her role as a "simple mum" who they had not taken into account. This confirms the finding of section 4.1.3 that the representative of the distressed mothers' website sees herself as standing up against the government.

The representative of the NVKP also thinks the distressed mothers' and his own dossier on the HPV-vaccination played a big role originating the discussion.

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| 23) | <b>I:</b>    | Yes, you already said, [the discussion] became bigger and bigger. Can you indicate why it became bigger and bigger?  |
|     | <b>NVKP:</b> | Well, because in particular people like Anneke Bleeker [of the distressed mothers' website] showed up. So at first Gardasil came onto the market [...] and from the very beginning, it became clear that this vaccine had some very nasty, unpleasant side effects for some girls. Video clips were created, with weeping parents who lost their daughter because of it, or had a daughter who had become severely handicapped. And that was all linked to that Gardasil and that was for instance used by someone like Anneke Bleeker on her website, but also others provided this kind of information and in the end that's what the RIVM denoted as old wives' tales. So they didn't originate from the NVKP, but they got attention, because we produced that dossier. Well, then the public saw there was a negative side and they copied the story. |

The respondent frames his association as a facilitator for the negative side of the HPV-vaccination story. He distances himself from being the origin of what the RIVM dismissed as 'old

wives' tales', but he does credit himself for collecting the information and being a platform for others.

The representative of the RIVM also thinks that anti-vaccination movements caused the discussion at least for a large part (in fragment #20 she already spoke of the critical researchers as being an aspect).

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| 24) | <b>I:</b>    | Can you describe how the discussion about the HPV-vaccination came about, according to you?  |
|     | <b>RIVM:</b> | Came about... Hmm. I find that hard to tell, [...] but I do think that the Association Critical Jabbing and Mrs. Anneke Bleeker [of the distressed mothers' website], that they were the starting points of the unrest that was created. |

The respondent calls the two anti-vaccination movements the starting point of the unrest. In her opinion they were the two stakeholders who spread the negative stories about the vaccination and with that made it difficult for the RIVM to communicate their own message.

The anti-vaccination movements mostly construct their own campaigns as the start of the public unrest about the HPV-vaccination. Although these anti-vaccination movements seemed to have played a role in the discussion, mainly as bearers of negative information about the vaccine, not all respondents point in their direction as the cause for the discussion. There are also respondents that acknowledge these movements as a source of negative information, but they lay responsibility with the media that gave these movements a platform to spread their opinions.

#### 4.2.3 DIFFERENT STAKEHOLDERS CONSTRUCT NEGATIVE MEDIA COVERAGE AS A CAUSE FOR THE DISCUSSION

As we saw in section 4.1.1 the critical researcher distanced herself from the public discussion, because she just wanted to give a voice to the other side of the discussion within the Health Council. However, her article was framed by others as a cause for unrest.

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| 25) | <b>I:</b>    | So first it [the advice] came from the Health Council, your article was to nuance that, but then again the media exaggerated that story.  |
|     | <b>CrRe:</b> | Translates it to: not doing it [vaccinating] at all, yes.   |
|     | <b>I:</b>    | Yes, so, what role did the media play then, according to you?   |
|     | <b>CrRe:</b> | Well, a very big role, yes, but from all sides. Of course at first there's the media advertising for the product. But well, the media, it's exactly like you just said. The media turns it into a very excitatory discussion. And they preferably include emotional stories and such. |

The respondent constructs the media as a cause for her article to become such a hot topic, by stating that they make the discussion spicier than it has to be, according to her. With that she indirectly points to the media as a cause of the discussion.

The broadcast of Zembla, about the role of the pharmaceutical industry in the introduction of the HPV-vaccine, is mentioned by several respondents as playing a part in the discussion. The representative of the RIVM mentioned the media in an earlier fragment (#16), but later in the interview she starts again about the role of Zembla.

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| 26) | <b>RIVM:</b> | And one other thing, is this context, don't forget, the broadcast of Zembla, in October. That's probably even, so even before the things I just mentioned. I think that's, so to speak before the publication of [the critical researchers] [...] So speaking of time, you asked, what started it all, right. Well, that's of course... I don't know if you saw it? That's of course a very tendentious, critical broadcast. |
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This respondent constructs the broadcast of Zembla as one of the aspects that started the discussion, with that she constructs this negative media attention as a cause for the discussion. She explains how this affected the communication with the public by the RIVM.

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| 27) | <b>I:</b>    | And what role did, you named it first, we did not discuss it any further yet, the NVKP and Anneke Bleeker, what role did they play?   |
|     | <b>RIVM:</b> | Well, they have, in many different ways they told their story. Anneke Bleeker on television, I think she was interviewed by [...] NOVA [TV-program about the stories behind the news], she didn't appear in the studio, but short clips were edited in between. [...] And then there were stories from America, about girls who had become handicapped for life as a result of the vaccination, well. [...] If you were to get your daughter vaccinated tomorrow and you're obviously not an expert on the subject, wouldn't you think ten times before getting your daughter vaccinated? I, well... But, ok, they depute it and I can try to refute it at that moment, but against such a serious image, you can be nice letting [the National Vaccination Program manager] speak for two minutes, but can you take away the fear? I doubt it. |

She states that it is not possible for her to refute these negative stories about the vaccine that are shown on television and therefore she constructs the media to play a big role in making the HPV-vaccination an issue.

One of the vaccine producers also thinks media played a part in causing unrest.

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| 28) | <b>I:</b>    | Yes, and what role did the media play according to you, in the establishment of the unrest, in the Netherlands?  |
|     | <b>Pha2:</b> | Well, look media, if you're talking about social media, that's where it started, that has been the source of the unrest. And with social media I mean YouTube, Facebook and Hyves [Dutch social network site]. Maybe Facebook not so much back then, but mainly Hyves and YouTube, which were being used at that moment. At that time Hyves was still big and the traditional media, so to speak, the regular prints and radio, TV also from time to time, they had a big influence on the debate, that's where the unrest was also created, by several journalists who really, well, they thought it was interesting. They provided a stage for critics, and that's not the fault of the media by the way, because I feel the media do what they have to do, and that's being critical and investigate. [...] |

This respondent points towards social media as well as traditional media as a cause for the unrest, by claiming that they provided a stage for negative stories. But he doesn't blame the



media for causing unrest, because he constructs it as a part of their job. Later he explains who he then thinks is to blame:

29) **Pha2:** [...] But it has been a discussion that the government totally, and I really feel that's the government's responsibility, that they let get out of hand totally: by not responding, doing the wrong things, right, filing lawsuits against doctors. Well, I don't think that's how it works in this world. [...] Well, and what you've got, you see, then there are still the traditional media, the government websites, well, where information could be found, which was correct in itself, but hidden away so far, that I, as a consumer, even have to search, so, well, that has not been an answer really.

So the respondent points to the government for not responding at all or responding in a wrong fashion. The science journalist agrees that the media are not to blame for causing the discussion.

30) **I:** And what role did the media play? In the discussion?

**ScJo:** [...] Do media really play a role in that? They more a sort of platform for opinions. [...]

**I:** Well, you can think for instance of a broadcast of NOVA, a broadcast of Zembla, [a broadcast] of Radar, I don't know if you saw those?

**ScJo:** Yes, well, anyway, that's responsive for a large part. There are researchers who have an opinion and then they create, Zembla creates a program about it. [...] Look, I'm aware of how media work, but their role in the discussion is obviously a lot less clear, if people actually care for it or not.

**I:** Yes, well, Roel Coutinho did mention that the media paid too much attention to certain parties and with that giving a voice to certain people who, well, yes... He once used the the phrase old wives' tales.

**ScJo:** Yeeees, but that's not completely fair of course. It's his job to quell those old wives' tales and to make sure they can't originate in one way or another. If he's running a poor campaign and those old wives' tales can proceed, well, then he has done something wrong.

The science journalist turns around cause and effect in this last fragment. He states that if the government had their message straight from the beginning, there would not have been room for old wives' tales and therefore there would be also less for media to communicate about. With that the science journalist agrees with the vaccine producer and they are not alone in criticizing the government, as is discussed in the next section.

Summarizing several respondents construct the media as a playing a role in the start of the public discussion. First of all they blame the media for focusing on negative aspects, as with the article of the critical researcher that was framed as anti-vaccination instead of the critical sound it was meant to be. Secondly, they blame the media for providing a platform for stakeholders who want to spread negative information about the vaccine. However other respondents also state that it's not fair to blame the media, because they are doing their job and it's the job of the government to refute negative information.

#### 4.2.4 DIFFERENT STAKEHOLDERS, INCLUDING THE GOVERNMENT, CONSTRUCT GOVERNMENT COMMUNICATION, IN TERMS OF BOTH CONTENT AND FORM, AS A CAUSE FOR THE DISCUSSION

In the previous section a vaccine producer and the science journalist point in the direction of the government when it comes to the question of who is responsible for the discussion. The vaccine producer emphasizes the role of the government in the next fragment.

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| 31) | <b>I:</b>    | Could the discussion have been prevented completely do you think?   |
|     | <b>Pha2:</b> | Yes, look, it's ok to have a discussion. But if you just, from the very beginning, had intervened and being the government, had joined the discussion, then you could have saves yourself a lot of troubles, that I'm convinced of. If you had made clear what your point of view was and had taken a stance and well... That's for sure. |

By stating that the large scope of the discussion could have been prevented by adequate government communication about the vaccine, the respondent constructs government communication as a cause of the discussion. He cites several shortcomings: the government joined the discussion too late, did not state their message clearly and did not take stance.

The science journalist, who criticized the RIVM already in the previous section, thinks that the government underestimated the situation.

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| 32) | <b>I:</b>    | What role did the government play in the development of the discussion? Earlier you mentioned the pieces; they had to pick up the pieces. Why did they have to pick up the pieces?  |
|     | <b>ScJo:</b> | Well, the Minister had decided it should be introduced, on the recommendation of the Health Council [...] while there was still a public discussion going on. And that makes it difficult to implement something and that's the task that was handed to the RIVM, just because they're in charge of the National Vaccination Program, but this was something completely different. And in fact they were completely not equipped in my opinion, although I think they thought so themselves, to design a suitable program to convince people it is useful, right, to refute the Association of Critical Jabbing, also to reply to researchers who joined the discussion. I feel they let it, but that's my observation from a distance, completely slip through their fingers. They completely underestimated what the Minister asked them to do. |

The respondent constructs the RIVM as the organization to refute messages from the NVKP and from critical researchers and concludes that they were not equipped to execute this task in an adequate fashion, because they underestimated the task at hand.

The member of the Health Council also thinks the government underestimated the situation.

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| 33) | <b>I:</b>    | And what role did the government play in the discussion? In the way they introduced the vaccine in the end?   |
|     | <b>HeCo:</b> | Well I think the RIVM did not take the social media into account. They did acknowledged that, that they maybe didn't act conveniently, that they relied too |

much on the idea that, well, that everyone will accept it at face, when something is offered to them.

The respondent does not only criticize the message of the government, but also that the government did not take social media into account. Furthermore, by stating that the government maybe thought everyone would just accept the new vaccine, the respondent blames the government for not communicating in the proper fashion and with that she constructs the government as responsible for a part of the discussion. Remarkably this view is partly confirmed by the government itself.

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| 34) | <b>I:</b>    | Yes. So if you have to put the finger on a sore spot, if I can call it that, it's the initial communication to citizens?  |
|     | <b>VWS1:</b> | Afterwards. That's afterwards, because I'm of the opinion that several aspects coincided, [...] if we had that all figured out, and explicitly had realized all that and had made it clear for ourselves, we already might have decided back then, to chose another tenor in the communication. That we didn't.   |
|     | <b>VWS2:</b> | Well, I think... On that topic I have a slightly different view, but I'm not sure either, I mean, it could be that it coincided; it could also be that we initiated it, to let it coincide, through this vaccine. I have a bit of a feeling that it, but well, I studied physics once, that it formed sort of a condensation nucleus, for these kind of opinions, which had a relatively easy focal point to manifest their opinions.                                   |
|     | <b>VWS1:</b> | I can imagine that's the way you see it.  |
|     | <b>VWS2:</b> | But there are two sides. I mean, I'm not sure what's true either. I do know that it's true, that we treated it, in our communication and during the introduction, as a classical vaccine. And I think that, with the knowledge we have now, has been naïve. Because it wasn't a classical vaccine, not because of the characteristics of the vaccine, not because of the characteristics of the children and not because of the characteristics of the target audience. |

One of the respondents from Ministry of Health looks back at the communication strategy as naïve. He does this by constructing the vaccine as being different from the vaccines that are already in the National Vaccination Program and therefore communication that was appropriate for a "classic vaccine", was not sufficient for the HPV-vaccine. This confirms the thoughts of the member of the Health Council, who stated the government relied too much on the idea that everyone will accept a vaccine at face, which is the case with a "classic vaccine".

The gynecologist also thinks the government communication fell short for the situation.

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| 35) | <b>I:</b>    | You just said: the response of the RIVM wasn't very elegant. How would you describe that reaction?  |
|     | <b>Gyne:</b> | Well, they didn't stick to their own identity, to their own strength, which is describing and explaining how well the RIVM already, back then and now still, handles the National Vaccination Program, with the vaccines that are included. And they didn't confine themselves to the content, but they also spoke about form and that's unwise. And regarding the discussion about the content, they |

should have taken the specific population more into account, young girls at the age of twelve and the catch-up campaign, thirteen through sixteen, that you, when you give them a voice in whether or not to come [...] that you should approach them in a very different manner. That such communication is done in a very different way. And that's something every parent with children in that age group can tell you. Like myself. And that went wrong and was done wrong.

The respondent criticizes the government for both the content and the form of their communication, although it does not become clear what he means with the form. The respondent criticizes the content of the communication for not being matched to target group consisting of teenage girls.

So different respondents, including the government itself, construct the communication with the public by the government as falling short when it comes to both content (not tuned for young girls and not taking into account the specifics of the HPV-vaccine) and form (not using social media) and therefore it left room for a discussion. The government agrees, with hindsight, that they did not handle the situation in a proper manner.

#### 4.2.5 DIFFERENT STAKEHOLDERS IDENTIFY A PUSH BY THE INDUSTRY FOR THE INTRODUCTION OF THE VACCINE AS A CAUSE FOR THE DISCUSSION

A final cause for the discussion as constructed by the respondents has to do with the producers of the vaccine: the pharmaceutical industry. Several respondents point to the unrest they caused by communicating with the public.

- 36) **I:** Did the pharmaceutical industry play a role in other ways [except in subsidizing research], in the whole discussion, in the whole introduction?
- CrRe:** Yes, absolutely, that ehm, yes I think that they formed a big incentive for the discussion, because well, there were two raids at the, at both of the companies. Because they thought they were advertising in an illegal manner, because in the Netherlands you're not allowed to advertise for medications of course. But what did happen, there was advertising for a disease. Cervical cancer was suddenly, everywhere it emerged. But well, it's not such a big deal in the Netherlands, cervical cancer is really very well under control due to public screening. And suddenly it was everywhere, Angela Groothuizen [a Dutch celebrity] of course with her commercial about protecting your daughter and of course that provokes women, everybody wants to protect their children, so that, well.

The critical researcher mentions the industry as a force for bringing cervical cancer under the attention of the public. She does not criticize them for doing this, but she does acknowledge it played a role in the development of the discussion.

- 37) **I:** What role did the pharmaceutical industry play?
- HeCo:** Well they really started advertising a lot. And they didn't play that very smart. Because I think that caused, I think that also played a role, people to get the idea that a lot of commercial interest were involved with it. They organized that information evenings were being held in hospitals. Well, you see, if there's a new antihypertensive on the market, then there is also no one going to an

information event in a hospital to get informed by an internist. But that's what they actually did in this case and that, I thought that wasn't smart and so I always refused to contribute to that.

The member of the Health Council disapproves of the way the vaccine producers tried to bring their product under the attention. She believes this may have caused people to think that commercial interests played a large part in the introduction of the HPV-vaccine and she implicitly frames this as a negative aspect.

38) **I:** You also said that they [the industry] pushed to get it [the vaccine] through. What role did they play there?

**ScJo:** Well, ok, their job, their job is of course to sell the vaccine, which they developed for a lot of money. So they would like governments to embrace their vaccine and adopt it in the vaccination program. And, well gosh, they try to do that by all means possible. Most of the time in a legal way, but sometimes a little bit in an illegal way.

**I:** What your opinion of how that went?

**ScJo:** Well, I think it's so incredibly stupid to, even before a decision has been made by the government, address the guilt of mothers. That's something you should refrain from when you don't have a good reputation. I mean, Albert Heijn [large Dutch supermarket chain] would be able to pull it off, but the pharmaceutical industry should, in my opinion, lay low in these kinds of situations, but well, I'm not the one to give PR-advice, so I don't know. But I have the feeling that they already ruined a lot for RIVM later on. Because they came with the same message, but then official, and well, then, then it's a lot harder.

The science journalist criticizes the pharmaceutical industry for their communication with the public, before the Health Council came with their advice. He reasons that they already had a bad name among the public and therefore their messages had a negative influence on the message of the RIVM when they called the girls up for the vaccination.

The gynecologist constructs the pharmaceutical industry as the initiator of the discussion in the Netherlands.

39) **I:** How did the discussion about the introduction of the HPV-vaccination come about, according to you?

**Gyne:** That is really general. How did the discussion come about? In other words: who initiated it? That's something you could distill from that as a first question. Then I think that we must state that the driving force for it to become a topic in the Netherlands, has been the pharmaceutical industry.

**I:** And how does it become a discussion from there?

**Gyne:** They created a topic from it, not only among the specialists that are directly involved, among people like me. But they have [...] for reasons of their own, provided information to others. And that goes wide, that goes from people in politics, members of parliament, government agencies, but also the public media by constantly providing press-releases, they have deliberately chosen, I think, I wasn't there, to turn this into a discussion in the Netherlands.

The respondent describes the role of the pharmaceutical industry as supplying information to several different stakeholders. This way the pharmaceutical is constructed as the starting point of the discussion, because they made the HPV-vaccination into a topic of discussion for the different stakeholders.

One of the vaccine producers confirms that they played a role in providing information to stakeholders and he explains what their motives were.

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| 40) | <b>I:</b>    | And ehm, can you still play a role in that discussion, as a pharmaceutical company?  |
|     | <b>Pha2:</b> | No, we have, as a pharmaceutical company you are not allowed to communicate with the main public about your products, so we have had to stand on the sideline with our hands behind our backs.   |
|     | <b>I:</b>    | Alright. But if I'm well informed, the pharmaceutical companies did call for attention for the disease, by means of, for example Sanofi, also a commercial. What's goal of that, of calling for attention?   |
|     | <b>Pha2:</b> | We did market research, far before the vaccine was introduced of course, on what people actually know about the disease, because it is a pretty complicated story to explain. [...] Well, it turned out that people had no clue about how common the disease is, how you can contract it and what you can do to prevent it. So we decided, and that's something you can do as a pharmaceutical company, we're going to make people understand what this disease means. [...] Then a fairly large campaign was launched to make people aware of what it is, with a website and a Dutch celebrity, with all the trimmings, to at least provide information about what is exactly going on when you have cervical cancer. |

The vaccine producer states that they started a campaign to get the public in the Netherlands informed about the disease. They thought this was necessary, because they supposed that without that knowledge people would not understand what the vaccine was for and would not get themselves vaccinated.

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| 41) | <b>I:</b>    | Because what would happen if you, if you, if that awareness would not be there?   |
|     | <b>Pha2:</b> | Well, then I think you will have a harder time in getting people motivated to get an injection, because then nobody understands why it is actually necessary. [...] Like I said, getting a note from the government, saying you should get vaccinated, that just isn't enough anymore to get people motivated. You have to explain to them why it is necessary and then, that also involves explaining what kind of disease it is and how it originates and, well, everything surrounding that. [...] |
|     | <b>I:</b>    | Ok. Do you think the campaign had the desired effect?   |
|     | <b>Pha2:</b> | That's hard to say. I think... Yes, well, it did, let's see, if you're talking about awareness among people, for sure. Because we did measure that, did that market research lead to a detectable increase in knowledge, and that was surely the case.  |

The vaccine producer explains why he thinks that their campaign was necessary. He does not link their campaign to the discussion and the unrest about the HPV-vaccination and with that he does not take responsibility for the discussion and the unrest among the public.

The other vaccine producer is also not very critical of the role of the pharmaceutical industry in the discussion about the HPV-vaccination.

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| 42) | <b>I:</b>    | There have also been journalists who were looking for, who focused on the supposed dependency, independency, of for instance the Health Council or other people who work for the government. What do you think of that?   |
|     | <b>Pha1:</b> | Well, I think it's very healthy and that it's very important, that everyone can be assured, and so it should be, that advice, consultancy and besides also decision making at the ministry, that it takes place independent. [...] when it comes to independency the first thought is always: industry. But I think you should make that independency much wider and it should be defined clearer. Because for instance, what your question here, what it doesn't cover, but what is very interesting is to see if researchers are independent from their self-interest. Rather than possible funding by the industry, but researchers, well, they have to haul new projects, from the NWO [The Netherlands Organization for Scientific Research], from other subsidizing organizations that exist. [...] |

When asked about the suggestion that journalists have made about influence of the industry on scientists and experts the respondent does not analyze the role of the industry, but he points to other forms of conflicting interests. Later in the interview he responds to possible appearance of conflicting interest caused by the pharmaceutical industry.

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| 43) | <b>I:</b>    | Yes, and do you attempt to help and take away that appearance [of conflicting interests]? Are you trying to make sure that appearance is not there? Do you worry about that?  |
|     | <b>Pha1:</b> | Well, you see, it's something you always have to think about carefully. So like I mentioned earlier, if we let scientific research take place, [...] that's a choice you make as a vaccine producer, to finance that, and then there are already people saying "oh, wait a minute, that's funded research, that man, that expert, is doing research funded by a vaccine producer who has an interest". Well, that's one way to put it, you could also say, the vaccine producer is in need of independent experts, who try to use the experience they acquired, to underpin, so to speak, the evidence for the effectiveness of their product, as well as possible. And that's of course out perspective. [...] |

The respondent acknowledges that there is criticism of possible conflicts, but instead of explaining what the industry can undertake to take away this appearance, he describes the other side of the story, which is his own point of view. Later in the interview he adds:

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| 44) | <b>Pha1:</b> | [...] The fact that we are working with independent experts, who we offer, fully transparent, and on contract basis a compensation, well, who, the same research as he writes in his research proposal, would also deposit it in the same way at a subsidizing government agency, well, those are the principles along which we work in the Netherlands. And you can be very critical about that, you can look for all kinds of things, but the facts are the facts. |
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Again the respondent explains the way the pharmaceutical industry works, but again he is not critical about the way it works. He states that they work following the principles as they apply in the Netherlands and he uses that to refrain himself from analyzing the role of the pharmaceutical industry critically.

For the representative of the distressed mothers' website the pharmaceutical industry plays a far greater role than only causing a discussion about the HPV-vaccination.

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| 45) | <b>DiMo:</b> | It [the review of the book "Chemo? Or do I have a choice?"] was not allowed in the newspaper. That book, that is quite revealing on a lot of areas [inter alia chemotherapy] and that's not allowed.   |
|     | <b>I:</b>    | By whom is not allowed then?   |
|     | <b>DiMo:</b> | Oncology [department of the Alkmaar hospital]. Cancer is a disease they say. But cancer is an industry. And the Queen Wilhelmina Fund [fund against cancer] will never be abolished, because it involves top salaries. There are more people working in the cancer industry, than there are people who have cancer, so to speak. |

The respondent constructs the pharmaceutical industry as having so much power that they can prevent negative information, in this case about chemotherapy, from getting media attention. By constructing the role of the industry this way she has an explanation for all actions that she identifies as undertaken against her own anti-vaccination campaign.

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| 46) | <b>I:</b>    | What role did media play, in the discussion, according to you?   |
|     | <b>DiMo:</b> | Well, the media are neither free. There is no freedom of press in this country. And that just noticeable in all areas, the way something is posted or not. And how you're, ehm, manipulated, how they write about you, things you've never said and which they easily post in the newspaper as if you said it. Well, that's also one big story. And they are also monitored by the government. |

The representative of the distressed mothers' website describes the government as being influenced by the pharmaceutical industry and therefore they are the driving force for the media that oppose her in her campaign. By describing the role of the industry as she does, she constructs the industry as being a cause for the discussion.

Summarizing, it can be stated that nearly all stakeholders point to the industry as playing a role in causing the discussion. They are criticized for starting a campaign to raise awareness about cervical cancer. They are said to have a bad name among the public and therefore this marketing campaign had an adverse effect. The representative of the distressed mothers' website attributes an even greater role to the industry, accusing them of influencing both government and media. Meanwhile the two representatives of the vaccine producers acknowledge that there is critique on their actions, but they are not very critical about their own role. The vaccine producers more or less say that they work the way they do and there's not much they can do about that. They mostly point to the government for failing to communicate properly with the public.



This concludes the results on how stakeholders construct the key issue in the discussion about the HPV-vaccination and what they define as the causes of the discussion. Now it's time to take a closer look at how the stakeholders view the role of science in the discussion. The results have already shown that several respondents use science to discriminate between a scientific and a public discussion. The latter is said to be based on opinions that are not based on science and the next section will show how the participants of this public discussion feel about this. It is not to be expected that for instance the anti-vaccination movements will agree that their opinion is not based on science. Therefore the results should give insight in the different ideas that exist about the use of science by the different stakeholders.

### 4.3 HOW DO THE STAKEHOLDERS CONSTRUCT THE ROLE OF SCIENCE IN THE DISCUSSION ABOUT THE HPV-VACCINATION?

This section gives an answer to the question how the different stakeholders construct the specific role of science in the discussion about the HPV-vaccination.

#### 4.3.1 ALL RESPONDENTS CONSTRUCT SCIENCE AS THE SOURCE OF THEIR INFORMATION FOR THE DISCUSSION

In section 4.1.1 we saw that several stakeholders make a distinction between a scientific and a public discussion. This distinction implicates that these stakeholders are of the opinion the public discussion was not based on science, but as we will see all respondents refer to science when asked where their information comes from.

|     |              |   |
|-----|--------------|---|
| 47) | <b>I:</b>    | Where did the first information come from, about which the discussion went?   |
|     | <b>CrRe:</b> | From literature. Well at least, what we had a discussion [about], of course at a certain moment the discussion was held in broader terms. But what we, for the advice of the Health Council and among scientist it was of course based on scientific facts. |

In this fragment the critical researcher clearly constructs science as the input for the discussion among scientists and within the Health Council. This fragment is also another example a distinction being made between a discussion among scientists and a public discussion, of which the respondents implicitly states that is was not based on science.

One of the vaccine producers already constructed science as the input for the scientific discussion in fragment #3, which is partly repeated here.

|     |              |   |
|-----|--------------|---|
| 48) | <b>I:</b>    | What role did scientific information play in the discussion, according to you?  |
|     | <b>Pha2:</b> | Well, in the public discussion little. Too little. In the real discussion so to speak, among those who, well, decide, among the Health Council and the RIVM, a lot. I think that that, there it has really has been on basis of pure facts. [...] |

This respondent constructs science as the input for the discussion among scientists and policy makers and he describes science as “pure facts”, by which he seems to emphasize that it is the valid input for the discussion.

So the stakeholders that make a distinction between a scientific discussion and public discussion construct science as the input for the former discussion and define that as the difference between the two discussions. However, the stakeholders that are against the HPV-vaccination do not agree with this description. In the next fragment the respondent from the NVKP explains what he thinks is the basis for the statements of his organization.

49) **NVKP:** [...] What we as NVKP stand for is that the statements we make, they all have to have a scientific base. Right, so they have to, that shouldn't be something like, a parent clamoring “my child died because of a vaccination”, that we then say, come on, that vaccine should be banned.

The respondent states that the NVKP bases itself on scientific findings to participate in the discussion and he distances himself from people who base themselves on emotional stories. This means that while other stakeholders speak of a public discussion that is non-scientific, this respondent is clearly of the opinion that he is participating in a scientific discussion.

In line with the respondent of the NVKP, the representative of the distressed mothers' website also states that she bases herself on scientific findings.

50) **I:** What role did scientific information play in the discussion? How do you use it yourself?  
**DiMo:** Well, what scientific information? Originating from?  
**I:** Ehm, well, scientific information in the sense of published articles.  
**DiMo:** Look, objective scientific information, that's something we value. But so called scientific information from mister Osterhaus [a public expert on the areas of virology and influenza] and his colleagues, we do not value that, because there are interests behind it.

The respondent also values scientific research, just like the other stakeholders, only she also states that there is a difference between the scientific information that she bases her opinion on and the scientific information used by scientific experts that work for the government, like Ab Osterhaus. In the next section this aspect is further elaborated.

#### 4.3.2 SEVERAL RESPONDENTS MAKE A DISTINCTION BETWEEN THE SCIENCE THEY USE AND THE SCIENCE OTHER STAKEHOLDERS USE

In the previous section we saw that all stakeholders construct science as the input for the discussion. But despite everyone talking about science, the respondents do not seem to be talking about the same thing.

In fragment #50 the representative of the distressed mothers' website pointed to a difference between the science she uses and the science public experts that work for the government use.

She states that the difference lies in the fact that the scientific information used by the government is the result of conflicting interests and has therefore no value to her. This means that although both stakeholders claim to base themselves on science, apparently a distinction can be made between different forms of science. By making such a distinction the arguments of stakeholders who use different science can be framed as invalid.

In the next section the representative of the distressed mothers' website further discusses what the difference is between scientific articles she uses and those used by the government.

- |     |              |  |
|-----|--------------|--|
| 51) | <b>I:</b>    | So you did have contact with, as they're called, experts of the Health Council. Did you also have contact with other researchers?  |
|     | <b>DiMo:</b> | Well, like I said earlier, we get reports, worldwide, from doctors, from people with an objective point of view, but who are also ridiculed by the same Health Council, RIVM and Minister group. |
|     | <b>I:</b>    | And what does objective mean to you?   |
|     | <b>DiMo:</b> | Objective means that you don't have interest with the pharmaceutical industry. No interest with whether or not to inject and swallow. I mean I don't have any stocks, I'm not getting paid.      |

The respondent makes a distinction between researchers that are objective and researchers that are not objective. She states that the difference between these groups is that the objective researchers are free of interests and the researcher that are not objective benefit from the introduction of the vaccine. She also states that the government refutes the scientific articles that she has as a source. In turn, the respondent states that the scientific research used by the government to base their decision on is not objective either.

- |     |              |  |
|-----|--------------|--|
| 52) | <b>I:</b>    | Are there any objective scientists who say that vaccinating is a good thing? |
|     | <b>DiMo:</b> | No, there are none.  |

The respondent states that there are no objective researchers that say that vaccinating is a good thing. In other words, she defines any scientific information that concludes otherwise, as being influenced by a conflict of interests. This way she leaves only room for a discussion based on the scientific research that she uses for her cause.

Where the representative of the distressed mothers' website defines her sources of information as the only objective sources, the respondent in the next fragment defines the information that the RIVM uses as the objective information.

- |     |              |   |
|-----|--------------|---|
| 53) | <b>VWS2:</b> | Look and we always provide information, about vaccines in this case. Specifically on the RIVM website, passive information, of which we are of the opinion that it is objective information. Look and if you think, by definition, that the RIVM or the government provides non-objective information, then there is nothing we can do about that. Because, I mean, that's an opinion, that's perception, which is difficult to [expose] from the other side- I mean, scientifically speaking that which the RIVM provides, is objective information. |
|-----|--------------|---|

She does this by stating that their information is objective “from the scientific point of view”, but now that we have seen that different stakeholders speak about different science, it seems as if this argument leaves just as little room for discussion about what is objective as the “conflicting interests”-argument of representative of the distressed mothers’ website.

In the last section we saw that the NVKP also sees science as the basis for the discussion. In the next fragment the gynecologist gives his view on the use of science by the NVKP in the discussion.

- |     |              |   |
|-----|--------------|---|
| 54) | <b>I:</b>    | Yes, because what they have to say for themselves, the NVKP, is that they do base themselves on scientific information and provide references and such. But you don’t agree, that they base themselves on science?  |
|     | <b>Gyne:</b> | Look when you base yourself on science, it means first of all that you have to base yourself on proper scientific articles and secondly that you filter the right information from the article and not just take a parenthesis out of context and then go and quote it. Well, you probably know just as well as I do, that when you look at the site of Critical Jabbing, you will find my name among the opponents of this vaccine. Well, that’s very interesting. Because you can say a lot about me, but I’m definitely not an opponent. |
|     | <b>I:</b>    | Why then, do you think, that they still say that they base themselves on science, why would they do that?   |
|     | <b>Gyne:</b> | Because it sounds right that way. They know very well that when you want to come across as convincing, you have to say that you base yourself on scientific articles, the opinion you have.   |

The respondent points out two interesting things about the use of scientific articles by the NVKP. First of all the respondent implicitly states that the NVKP does not make use of ‘good scientific articles’, so apparently to the respondent it makes a difference what kind of scientific articles someone uses, in order to be taken seriously by other participants of the discussion. Secondly, the respondent implicitly states that the NVKP does not use the scientific articles in the right manner, because they do not take ‘the right things from the articles’, so apparently to the respondent it makes a difference how someone uses scientific articles, in order to be taken seriously by other participants of the discussion. The respondent also explains what he thinks is the reason for the NVKP to use scientific articles as references in their dossier: he states that it is a way for the NVKP to come across more convincing.

The representative of the NVKP agrees that he gains credibility by using scientific articles.

- |     |              |  |
|-----|--------------|--|
| 55) | <b>I:</b>    | Ok, so you are trying with that [the use of science] to appear credible.   |
|     | <b>NVKP:</b> | We try to be credible, because for example, if you take a look at my HPV-dossier, there are dozens of source references. Right. So there is not a single statement being made, without a scientific study, being at the basis of it. |

The respondent explains that his dossier is credible because every statement is supported by scientific source, instead of being empty words. There is however a difference with the description as given by the gynecologist: the representative of the NVKP does not see credibility as the goal of using scientific sources, but as the result of it.

Concluding it can be said that although all stakeholders use science as input for the discussion, they all seem to use their own form of science. The respondents discriminate between the science that they use and the science that stakeholders they disagree with use. By setting aside the science used by others as not objective, stakeholders leave no room for a discussion about science. This raises the question how to deal with these different conceptions of science, because who decides which form of science is the correct one? It also has implications for the definition of scientific authority; if the stakeholders are talking about different science, what does the decline of scientific authority exactly mean?

The fact that all stakeholders use science as source for their information shows they value science and the information that it yields. In terms of scientific authority it could be said that science has authority in their eyes, because they see it as a valid base for their opinion and some use it to gain credibility. When asking the respondents to define scientific authority, one could expect insight in why they value science as much as they do. The last section already showed that science is associated with independency and credibility, so these terms are expected to be used when talking about scientific authority as well. The next section shows that although all stakeholders value scientific research, they are having problems with defining what scientific authority is.

## 4.4 HOW DO THE STAKEHOLDERS DEFINE SCIENTIFIC AUTHORITY?

This section focuses on scientific authority. The term is often used these days, but what do people mean by it? This section tries to answer that question according to the views of the stakeholders.

### 4.4.1 STAKEHOLDERS HAVE DIFFICULTIES FORMULATING A CLEAR DEFINITION OF SCIENTIFIC AUTHORITY

During the interviews it turned out that most respondents found it difficult to give a clear description when asked what they understand by the term scientific authority. The respondents that were able to formulate a definition gave varying descriptions.

|     |              |  |
|-----|--------------|--|
| 56) | <b>I:</b>    | How would you define scientific authority?   |
|     | <b>ScJo:</b> | Authority means that people listen to you, they don't have to agree with you, but they do listen to you. |

The science journalist states that people listen to someone with authority. He adds to this that authority does not mean that people agree with you; according to the respondent the fact that

you get attention shows that you have authority. The member of the Health Council gives another definition.

|     |              |   |
|-----|--------------|---|
| 57) | <b>I:</b>    | What do understand by the authority of science?   |
|     | <b>HeCo:</b> | That people accept that if experts consider something and have performed a study in a proper fashion, that on basis of that, choices are made about how we do things in healthcare. |
|     | <b>I:</b>    | Ok, so, accepting the advice of experts.  |
|     | <b>HeCo:</b> | Yes, that people accept the advice of experts.  |

The respondent defines scientific authority as people accepting that experts know what is best, based on scientific studies. This means the respondent defines scientific authority not only as people listening to the expert, as the science journalist stated, but that they also accept that the expert makes the decisions, without questioning the reasons for the decisions.

The representative of the NVKP defines authority in about the same way.

|     |              |   |
|-----|--------------|---|
| 58) | <b>I:</b>    | If you would have to define, the word authority, what proves authority?                                   |
|     | <b>NVKP:</b> | Authority, is when someone says something, that it actually happens, or that it's true, that's authority. |

The respondent associates authority with two things here: power and truth. He defines authority as having the power to make something happen or as having people believing that you speak the truth.

These three fragments were the only clear descriptions given by the respondents. If a conclusion could be drawn from these fragments it is that these respondents feel that scientific authority has something to do with the public paying attention to scientific experts, but it not quite clear to what extent the public should listen in order to speak of authority.

The finding that it is difficult to give a description of scientific authority is remarkable in the light of the recent discussion on the decline of this scientific authority. If it is not clear what scientific authority exactly means, how can we speak of a decline of this authority?

Although most respondents had difficulties with giving a clear definition of scientific authority, there were certain similarities in the descriptions that they gave. The next section discusses these similarities.

#### **4.4.2 SCIENTIFIC AUTHORITY IS ASSOCIATED WITH TRUSTWORTHINESS, CREDIBILITY AND INDEPENDENCY BY STAKEHOLDERS WHO CAN BENEFIT FROM HAVING AUTHORITY**

Two aspects that are associated with scientific authority by several respondents, and which are closely related, are trust and credibility.

|     |              |   |
|-----|--------------|---|
| 59) | <b>I:</b>    | A popular phrase these days is that the authority of science is at stake, that's what you hear in the media. What do you understand by the authority of science? What do people mean when they speak of it?   |
|     | <b>Vac2:</b> | Well, I think they mean, do you trust, as a regular Dutch citizen, as a consumer, what is stated by a scientist [...] I think that overall, if you say: "I'm an expert, I'm a doctor and I have patients in treatment and I think this is the best option", that that's really a very trustworthy sender. |

The respondent describes scientific authority as a relation between a scientist and the public, and he defines the key aspect in this relation as trust. As an example of a trustworthy expert the respondent points to a doctor, because he has experiences with patients.

The representative of the RIVM associates scientific authority with different aspects.

|     |              |   |
|-----|--------------|---|
| 60) | <b>I:</b>    | What do you understand by authority? When does someone have authority?  |
|     | <b>RIVM:</b> | Well, I think that authority has to do with, first of all with expertise, knowledge and skills. And another element could be, credible, persuasiveness, those kinds of elements are also contained in it. [...] |

The respondent associates scientific authority with two roughly things: expertise and credibility. She states that a first condition for scientific authority is expertise and knowledge, but someone also has to be credible or convincing. These last two aspects are related because someone who is not credible will probably not be convincing either.

|     |              |  |
|-----|--------------|--|
| 61) | <b>I:</b>    | And how would you define authority? What is authority?   |
|     | <b>VWS1:</b> | Well, that is both the government deciding what's best for you, or the government that you trust, that she acts in the best interest of, at least society, as well as the doctor that indeed says what's best for you. |

The representative of the Ministry of VWS also associates authority with trust. She relates this trust to the good intentions of the people with the authority. In other words the public needs to be convinced of the good intentions of, for example, a doctor in order to trust the doctor and thus for the doctor to have authority. In this light the actions of the anti-vaccination movements, who framed the discussion as standing up against the government in section 4.1.3, could be explained as these movements not believing in the good intentions of the government.

When authority is defined as the public listening to experts, it is something that the government can benefit from when they try to get their message across to the public. By associating authority with trust, credibility and good intentions they more or less put the finger on a sore spot, because in section 4.1.4 the government defined the key issue in the discussion as having problem getting their message across to the public.

Another aspect that authority is associated with by several stakeholders also has to do with the good intentions of scientific experts and that is independency. Several respondents think that

independency is a condition for having authority. They construct conflicting interests as forming a threat to authority.

|     |              |   |
|-----|--------------|---|
| 62) | <b>I:</b>    | But then that [the scientific method] is what science derives its authority from? That it's the only way for facts to-  |
|     | <b>CrRe:</b> | Yes, that's the, yes, once you... I don't think for example, that when a company tries to get the facts out on the table, a company that is producing a product themselves and that wants to prove how good their product is... Well, then you're completely not independent of course. So I do think it's the only tool... |
|     | <b>I:</b>    | So independency is in fact a condition for...?  |
|     | <b>CrRe:</b> | For that, yes, for that authority, I think so, yes.   |

The respondent draws a comparison between independent research and a company that performs research to show that a company has an interest in producing positive results and is therefore not independent. She does not explain how this independency leads to authority, but independency seems to be a condition for people in order to listen to an expert.

The representative of the NVKP also starts about independency when he is asked about scientific authority.

|     |              |  |
|-----|--------------|--|
| 63) | <b>I:</b>    | The last couple of months it is more and more stated that the authority of science is supposed to be at stake. What do you understand by scientific authority?                                   |
|     | <b>NVKP:</b> | For me that's not an expression I would use myself, scientific authority. For me it's the case that, a scientist should be as independent as possible, must be honest, must act ethically sound. |

The respondent does not give a definition of scientific authority, but he explains that in order for himself to listen to a scientist, that scientist should be independent. With that the respondent also defines authority more or less as being heard by the public and he defines independency as a condition for being heard.

Altogether, the respondents associate scientific authority with aspects like trustworthiness, credibility, good intentions and independency. These aspects are seen to be conditions for experts to have authority. It could well be that the experts and the government are lacking in some of these aspects, because the stakeholders that oppose the HPV-vaccination frame authority as a negative thing, as the next section shows.

#### 4.4.3 ANTI-VACCINATION MOVEMENTS ASSOCIATE SCIENTIFIC AUTHORITY WITH THE POLICY-MAKERS THEY ARE STANDING UP TO

In section 4.1.3 the representatives of anti-vaccination movements defined the key issue in the discussion about the HPV-vaccination as standing up against the policy makers. When asked about scientific authority these respondents give reactions that are in line with this view.



|     |              |   |
|-----|--------------|---|
| 64) | <b>I:</b>    | Yes, but science can be used, scientific research, to create authority? Am I saying it right? If I understand it correctly, you are trying with your organization, by basing yourself on scientific research, to come across as credible.   |
|     | <b>NVKP:</b> | Well, what we are trying, in fact what we are showing, is that this authority that you're speaking of, that bastion, that it contains cracks and that very easily other scientific research can be presented, as a result of which those people who are claiming: "come on you guys, we're authoritative and if we claim something then it's true", that that authority, is not omniscient, and is [not] unimpeachable and [not] that you don't have to doubt it. |

The respondent describes authority as a bastion that acts like it is omniscient and that very much tries to come across as authoritative. He states that the scientific research his organization uses can undermine that authority. This is in line with the findings of section 4.3.2 that different stakeholders are talking about different science. In this case it indicates that the representative of the NVKP is not opposing science in general, but he opposes the policy makers who claim to have scientific authority and he states they are using the wrong scientific research. In other words he describes the government and scientific experts as trying to use authority to influence the public. He sees it as the goal of his organization to show, using other scientific research, that this bastion of authority is not very well-founded.

The representative of the distressed mothers' website also defines authority as a negative thing.

|     |              |  |
|-----|--------------|--|
| 65) | <b>I:</b>    | I still have a question about the authority of science in society. Science has a certain kind of authority, experts have a kind of authority-  |
|     | <b>DiMo:</b> | What do you mean by experts?   |
|     | <b>I:</b>    | Yes, well, exactly, so that's my question.   |
|     | <b>DiMo:</b> | You know, an expert, who has his scientific reports being written by a ghostwriter, that is a big dolt to me. And, the majority, the vast majority of our population, follows each other like sheep. And that's nice and easy, because you don't have to think for yourself. |

The respondent does not give a definition of scientific authority, but her first association with authority and experts is that people follow experts blindly. She describes people who accept authority as sheep who follow one another without thinking for themselves. Later in the interview she continues about authority.

|     |              |   |
|-----|--------------|---|
| 66) | <b>I:</b>    | Do you agree with me when I say, there exists authority, whether that's science or government, because people do not think for themselves.  |
|     | <b>DiMo:</b> | Yes... This authority is just one big joke to me, really.   |
|     | <b>I:</b>    | Yes, but it exists. Because you just said yourself, people follow what they see, so the authority exists-   |
|     | <b>DiMo:</b> | Yes, but that's the whole point, people <i>think</i> , people <i>think</i> that it's a good thing. People <i>think</i> that the authority is right, well, the authority is not right and the authority is all manipulation. [...] What do you mean, authority?! I have no respect for it. |

When asked about authority, the respondent links it to the policy makers, the authorities, against which she is standing up. She recognizes that other people trust the government in making the right decisions, but she does not hesitate with stating the government is not right and that she is not one of the people who follow the government blindly.

Looking back at section 4.3.2 the representative of the distressed mothers' website stated that she values reports from objective scientists around the world. One could say that to her those researchers have some sort of authority. However, she does not think of these sources when asked about the term 'authority', so apparently in this situation she sees scientific sources as unrelated to authority.

Both stakeholders that are against the HPV-vaccination define scientific authority as something negative that is used to influence people, who incorrectly assume the experts that have authority, in making the desired decisions. This view exists despite of the value the stakeholders attach to their own scientific sources.

Looking back at all the results about the causes of the discussion, the role of science and the definition of scientific authority, what opinions are expected on the decline of scientific authority? On the one hand all stakeholders use science as a base for their opinion and the public disagreement among scientists is constructed as a cause for the discussion by several stakeholders. This can be explained as signs of the authority that science still has. On the other hand, when scientific authority is defined as people listening to experts and following the advice of experts, the low vaccine uptake, this can be explained as a decline of scientific authority.

## **4.5 TO WHAT EXTENT DO THE STAKEHOLDERS IDENTIFY A DECLINE OF SCIENTIFIC AUTHORITY IN THE DISCUSSION ABOUT THE HPV-VACCINATION?**

Now that the views of the stakeholders of what scientific authority is, has become clearer, it is interesting to see if they actually identify a decline of this authority in the discussion about the HPV-vaccination.

### **4.5.1 IN PARTICULAR RESPONDENTS FROM THE GOVERNMENT IDENTIFY THAT THE STATUS OF SCIENTIFIC EXPERTS IS NO LONGER A WARRANTY FOR AUTHORITY**

Several respondents, mainly on the side of the government, identify that scientific experts are no longer trusted based on their status as an expert. The respondents define it as a phenomenon of these days.

|     |              |  |
|-----|--------------|--|
| 67) | <b>I:</b>    | And why, do you think, the vaccine uptake was so low. What do you think moved parents to not go ahead and do it?   |
|     | <b>HeCo:</b> | I think the fact that the parents got the impression of, gosh, they're disagreeing, so it's probably not very clear. Well, and, some sort of new movement that the |

public doesn't accept any longer what the government, scientists, experts on a specific area all have to say. It seems like some kind of new movement, right?

The representative of the Health Council identifies a new movement in society, that the government, scientists and experts are no longer believed without question. In other words the respondent speaks of a decline of scientific authority and she feels it is something that did not happen before. This statement is in line with the definition that this stakeholder gave of scientific authority in fragment #57.

- 68) **I:** Do you think it's a phenomenon of this time, that this other [personal] side has to be shown [in the message of the government for the public]? That it didn't play a role before?
- VWS1:** I think it played a smaller role. I think that with the, with the social media and all it's easier spread. And with the declined trust in the government and the declined trust in white coats, right, so there is a bit more criticism.

In line with the representative of the Health Council, the representative of the ministry of VWS identifies a decline in trust in the government and in the "white coats", which is a metaphor for the scientific expert. It is interesting that she poses this decline in trust as a fact, nearly as something indisputable. However, when the respondent is asked if she can explain where this decline of trust becomes visible, it turns out she finds it difficult to find good examples.

- 69) **I:** You already mentioned less trust in the government and less trust in white coats. Where do you get that feeling?  
[...]
- VWS1:** Where do you get that feeling? I think that's a difficult question.
- VWS2:** Well, from the fact, a very simple example, I mean, I can, I think it was during the flu period, remember there was a broadcast of Pauw & Witteman [a talk show on current affairs], in which the chairman of the Dutch society of General Practitioners appeared, a GP himself. He was confronted with that lady [of the distressed mothers' website], who was of the opinion that there should be no vaccination. And his, in my opinion lofty phrase, was: how the hell did we get to a situation in which the opinion of a former nurse is held at the same level as the opinion of thirty experts who discussed it for five hours? [...]
- VWS1:** Yes, that could also be a bit the case, right. But that's also not "where do you get the feeling from?" but every opinion that is put on the internet is of equal importance, so to speak. But I do also have the feeling, that the trust in authority, or the preparedness for authority or something like that, that it is declining, has declined, but where you get the feeling from, I don't know.

When further asked about this decline of trust in science the respondent shows that it is not as clear as she stated earlier. The respondents are of the opinion that the view of scientific experts should be valued higher than the view of a lay person. However, the respondents feel these views were valued equally in the discussion about the HPV-vaccination and see this as an example of a decline of trust. This way the authority that has been given to a former nurse is constructed as competitive to the authority of the scientific experts and the respondents do not view the former nurse as a full conversation partner.

The representative of the RIVM also identifies that experts are no longer believed for being experts, when she is asked to explain what authority is.

|     |              |   |
|-----|--------------|---|
| 70) | <b>I:</b>    | What do you understand by authority? When does someone possess authority?   |
|     | <b>RIVM:</b> | Well, I think that authority has to do with, first of all with expertise, knowledge and skills. And another element could be, credibility, persuasiveness, those kinds of elements are also contained in it. But precisely this credibility is no longer the case these days, that someone who deposes something based on his expertise, is actually looked upon with a bit of suspicion. |

The respondent identifies a decline in scientific authority and she states that it has to do with credibility. She says that these days experts can't make statements based on their expertise, in other words she thinks that expertise is not a guarantee for credibility anymore and therefore that expertise is not sufficient anymore for the public to believe what someone says.

So stakeholders on the side of the government identify a decline in scientific authority, but they have difficulties explaining where they base their opinion on. A similarity between the statements of the respondents is that they express that the expertise of a scientist should be sufficient for the public to value what that scientist has to say. Other stakeholders also define a decline in authority, but they point to the government as the stakeholder that is experiencing a decline in authority, as the next section discusses.

#### 4.5.2 DIFFERENT STAKEHOLDERS IDENTIFY A DECLINE OF TRUST IN THE GOVERNMENT

Several respondents do not identify a decline in scientific authority, but think it is a problem of trust in the government which is playing a part in the discussion about the HPV-vaccination.

|     |              |  |
|-----|--------------|--|
| 71) | <b>I:</b>    | Do you agree that the authority is at stake?   |
|     | <b>HeCo:</b> | Well, I don't know exactly, that, that's the impression you're getting a little bit.   |
|     | <b>I:</b>    | And where do you get that impression?  |
|     | <b>HeCo:</b> | Whether it is the authority of science or the authority of the government? That I don't know exactly. It could very well be the authority of the government. But it is also exaggerated a bit sometimes. |
|     | <b>I:</b>    | How do you mean?   |
|     | <b>HeCo:</b> | Well, those nice quotes in the media.  |

The respondent states that she gets the impression there is a decline in authority, but she does not know whether it is a decline in scientific authority, or in the authority of the government. She does not give an example, but she does state that the decline in authority is exaggerated by the media, because it is a quote that sounds good.

In the next fragment one of the representatives of the vaccine producers explains what he believes people mean with the term 'authority'.

|     |              |   |
|-----|--------------|---|
| 72) | <b>I:</b>    | A popular phrase these days is that the authority of science is at stake, that's what you hear in the media. What do you understand by the authority of science? What do people mean when they speak of it?   |
|     | <b>Vac2:</b> | Well, I think they mean, do you trust, as a regular Dutch citizen, as a consumer, what is stated by a scientist. And I now happen to work at an agency who examines that trust every year, so we have a clear view of how this is developing over the years. And what you see is that the citizens' trust in the government is declining, it really drops every year. But that the trust of citizens in real experts is high and remains high, even slightly increases. [...] |

The respondent uses trust as a measure for authority. The respondent states that in his current work he surveys the trust in scientists and in the government and from this work he knows that the trust in scientists is still high, but the trust in the government is in decline. The respondent therefore more or less concludes that the scientific authority is still present, but according to him there is a decline in the authority of the government.

|     |              |   |
|-----|--------------|---|
| 73) | <b>I:</b>    | Yes. So if you have to put the finger on a sore spot, if I can call it that, it's the initial communication to citizens?  |
|     | <b>VWS1:</b> | Afterwards. That's afterwards, because I'm of the opinion that several aspects coincided, [...] in [a] time with certain groups getting more and more critical when it comes to vaccinating and also when it comes to the trustworthiness of the government. Right, you see that the citizens think the government is increasingly less trustworthy [...] |

The representative from the Ministry of VWS also points to a decline of trust in the government. She does not use this as a measure of authority, but she does think it played a role in the discussion about the HPV-vaccination.

#### 4.5.3 DIFFERENT STAKEHOLDERS DO NOT IDENTIFY A DECLINE OF SCIENTIFIC AUTHORITY

Some respondents do not agree with the idea that scientific authority is in decline in the discussion about the HPV-vaccination. They point to the value that is attached to the opinion of scientific experts.

|     |              |  |
|-----|--------------|--|
| 74) | <b>I:</b>    | Do you observe anything yourself, of the decline of authority, in the recent discussions?  |
|     | <b>CrRe:</b> | No.  |
|     | <b>I:</b>    | Or is it the case, that with all the attention the article has received, that it's more some sort of confirmation that it does have authority?   |
|     | <b>CrRe:</b> | Yes, because then it would have been, if you google on our article, then everywhere it's like, these are real, these are scientists, experts also saying this or that, you know, so I think that precisely the authority was used to, well, to sell the opinion. |

The critical researcher agrees with the interviewer that the fact that her article got so much attention is a sign of scientists having authority. She states that on the internet she sees people using her article for their, because it is article written by "real scientists". The respondent sees this as an indication of scientific authority.

Following this line of reasoning section 4.2.1, about the public disagreement among scientists, can be viewed as a sign of scientists still having authority. The fact that several respondents construct this disagreement as a cause for the discussion shows that they feel that the opinion of scientists is still valued. If a group of people without authority would have been openly disagreeing, this probably would not have been constructed as a cause of the public discussion.

|     |              |   |
|-----|--------------|---|
| 75) | <b>I:</b>    | Yes. Are you of the opinion that scientists <i>did</i> have authority in the discussion?  |
|     | <b>Vac2:</b> | For sure, they certainly have [authority], otherwise even half of the children would not decide to get vaccinated anyway. They did do it anyway and a lot of people went to their GP, to a doctor, and a lot of doctors said: no, go ahead, because it's safe and it's good. So authority has helped in this discussion definitely. |

The vaccine producer also thinks that scientists still had authority in the HPV-discussion, because he thinks a lot of people went to their doctor for advice and this confirms the authority of the doctor. He even states that the mere fact that half of the girls went to get the HPV-vaccination is a show of scientific authority.

|     |              |  |
|-----|--------------|--|
| 76) | <b>I:</b>    | Do you agree with the statement that the authority of science is at stake?   |
|     | <b>ScJo:</b> | Scientists do have authority; that shows from the amount of money flowing their way [for research]. But also from the fact that scientists who represent a different meaning, are being used by opponents. |

The science journalist has a different argument for stating that scientists still have authority: they still receive a lot of money for research. In the HPV-vaccination specifically he agrees with the critical researcher on the fact that her article being used by the opposition is a sign of scientific authority.

Altogether several respondents speak of a decline of scientific authority, but when they do, they find it difficult to explain why they think that there is a decline. Furthermore they make a distinction between scientific authority and the authority of the government. The respondents that identify a decline in scientific authority associate this with scientific expertise not being sufficient anymore to be heard by the public. The respondents that point to a decline of trust in the government speak of a lack of trust in the government as being a part of the problem. Besides the respondents that speak of a decline of authority there are several others that do not identify a decline in authority, but they point to the value that was attached to the opinion of scientific experts during the HPV-discussion.

## **5 CONCLUSIONS & DISCUSSION**

In this chapter the main findings of the research are discussed, together with the implications these findings have for the different stakeholders. Finally the limitations of the research are discussed followed by suggestions for further research.

### **5.1 MAIN CONCLUSIONS**

This chapter tries to use the results that the analysis of the interviews yielded, to answer the research questions presented in the introduction chapter: how do stakeholders construct the discussion in a case where scientific authority seems to in disrepute and how do they view the role of scientific experts and expertise in this case? Besides presenting the main conclusions this section also discusses the implications these answers have for the different stakeholders. Where relevant the findings are linked to what was said in the literature about these aspects.

#### **5.1.1 SCIENTIFIC EXPERTS SEPARATE A SCIENTIFIC FROM A PUBLIC DISCUSSION, WHILE ANTI-VACCINATION MOVEMENTS WANT TO JOIN THE SCIENTIFIC DISCUSSION**

One of the main points that have become clear during the interviews is that scientific experts define the discussion about the HPV-vaccination in a different way than the anti-vaccination movements do. The stakeholders that were involved in the discussion at the time when the Health Council gave its advice on the HPV-vaccination to the Minister, define this early discussion as a *scientific* discussion which was followed by a *public* discussion, in which they did not take part and which was not based on science. Scientific experts even stated that according to them the discussion was closed after the Minister made his decision about the introduction of the HPV-vaccination.

The discussion as described above is consistent with the analysis of discussion about the HPV-vaccination by Lips (2011). He argues that scientists often think they can strictly separate the scientific discussion from the political discussion, while the scientific discussion often also covers normative or political aspects. Lips states that it is this attitude that causes skepticism among the public, but it seems that it's not just the fact that scientific experts give advice about political problems that causes distrust. The idea that scientific experts have the exclusive right to decide on scientific matters also leads to skepticism.

Anti-vaccination movements are also talking about science as they claim to base their arguments on scientific research. They speak of the uncertainties that exist about the efficacy and the side-effects of the vaccine. Although the dossier of the NVKP was used by the Health Council in their advice, many scientific experts do not recognize the organization as a full participant of the scientific discussion. They even say the NVKP only uses scientific research as input for their point of view, because that makes them more credible. They are also accused of not using proper scientific research and not using the research in the right way. By making these accusations

scientific experts can still distance themselves from movements like the NVKP and evade a dialogue with them. Meanwhile the representative of the NVKP clearly wants to join the scientific discussion and he is annoyed by the way the facts are presented to the public, by the experts that want to close the discussion.

Myers (2004) argues that scientists often think they have the only claim to the truth and that their opinion is not open for evaluation. In a way this is what is happening when scientific experts claim that the discussion was closed after the Minister decided to introduce the vaccine in the National Vaccination Program. The scientific experts claim that they were discussing science, whereas the public discussion was about opinions that were *not* based on science. The scientific experts use science to distance themselves from people who do not have a scientific background and this way they seem to define who has the right to speak.

Interestingly enough, when asked about this scientific discussion within the Health Council, the stakeholders who make the distinction, indeed speak of a normative topic, rather than of a scientific discussion. The discussion seemed to have been about whether or not possibly saving 100 lives was worth the effort; there seemed to have been consensus about the (uncertainties of the) efficacy and the possible side-effects of the vaccine. This confirms Lips (2011) argument about the difficulties that exist when trying to separate the scientific from the political discussion. It is an indication that such a strict separation might not be the way to go in cases like this.

The way scientific experts try to distance themselves from the public discussion is also interesting in the light of the work of Collins and Evans. They opt for a situation where a core-set of experts can come to a consensus on specific matters that fall within their expertise, without the interference of others (Collins & Evans, 2002). This concept assumes such a core-set of experts can be defined in one way or another and that their conclusions will be accepted by the other stakeholders in the discussion. However in the discussion about the HPV-vaccination it seems to be the case that exactly such a distinction between a discussion among scientists and a public discussion is one of the problems that the anti-vaccination movements have with the current situation. The anti-vaccination movements are also talking about science, but their conclusions differ from the conclusion of the Health Council. However, the Health Council advice is not open for evaluation and this leads to skepticism at the side of the anti-vaccination movements, who openly ask what motives the Health Council can have to still give the advice.

Summarizing it can be said that the scientific experts try to establish a separation between a scientific discussion among experts and a non-scientific discussion among other stakeholders. In the first place this is problematic because it is exactly science, in the form of uncertainties about the working and side-effects of the HPV-vaccine, that is one of the points that other stakeholders want to discuss. In addition this separation is also problematic because the scientific discussion



that experts speak of, is not a purely scientific discussion, but also covers normative and political aspects. To say the least this separation does not seem to improve the relation between scientific experts and anti-vaccination movements.

#### IMPLICATIONS

So what can be done in order to improve this relation between the scientific experts and the public? According to Myers the main issues of the public are that the scientific experts distance themselves from the public and that their opinion is not open for evaluation. This situation can only be prevented if the views of participants with different opinions, such as anti-vaccination movements, are taken seriously and if they actually can be of any influence to the decision-making process. In other words after the Minister decided to introduce the HPV-vaccine to the National Vaccination Program, the discussion was closed in the sense that the end result was fixed. After this decision the anti-vaccination movements expressed their displeasure, but this could not make a difference anymore to whether or not the vaccination continued. However, it could have had an influence on the number of girls that got vaccinated. The file from the NVKP about the HPV-vaccination was even included in the Health Council advice. However, because the final advice of the Health Council did not reflected their ideas, this still led to irritation at the side of the NVKP.

Lips (2011) proposes Pielke's (2007) idea that scientists take the role of 'honest brokers of policy alternatives' who sketch different scenarios in consultation with all the different stakeholders. According to Lips could for example have led to scenarios in which the choice of vaccination was left to parents and their daughters who had to pay a part of the vaccines, or a scenario in which the demand for more research on the efficacy and side-effects was expressed. After these scenarios are formulated the policy makers have to argue which scenario is implemented and why.

So in order to prevent the public from feeling sidelined, anti-vaccination movements and other interested citizens should be involved in the discussion, before the Health Council produces an advice, and without rejecting their input on forehand. One way to accomplish this is the earlier mentioned 'honest brokers of policy alternatives' who can sketch different scenarios in consultation with all the different stakeholders. This process should be public and the results should be available for everyone who is interested in how the different arguments were weighed in the process of formulating an advice that sketches the possible scenario. Lips proposes to reserve the role of honest broker for scientific experts, but science communicators are of course suited for to impersonate as a mediator between the scientists and the interested public. The difficulty in this solution lies in finding the stakeholders and citizens that want to be involved in the discussion. This could for instance be done by analyzing earlier, similar cases, and by looking for interest groups that deal with the topic that is up for discussion. However, one can never know if everyone who is interested is included.

## **5.1.2 THE MAIN INCENTIVE FOR ANTI-VACCINATION MOVEMENTS IS ONE SIDED**

### **COMMUNICATION BY THE GOVERNMENT**

Another notable conclusion that can be drawn from the results is that the anti-vaccination movements have great difficulties with the government communication. As mentioned in the previous section the anti-vaccination movements argue that there are still uncertainties about the efficacy and side-effects of the HPV-vaccine, but they do not recognize this in government communication, which is far too “one-sided positive” according to them.

The representative of the distressed mothers’ website even describes herself as “thinking differently”, to indicate that she is standing up against the main stream, which is promoting vaccinations. Both she and the representative of the NVKP define their own communication as showing “the other side” of the message that the government is spreading. This skepticism towards the government also stems from a discrepancy between the advice of the Health Council, which seems to be nuanced, and the message that the government send to the public, which seems to lack this nuance.

This finding corresponds with the ideas of Brian Wynne, who argued that scientists need to admit the uncertainties that exist and show how unforeseen impacts are monitored and managed in order to show trustworthiness (Wynne, 2006). If anything becomes clear from interviewing stakeholders that are against the HPV-vaccination, it is that they do not think of the government as trustworthy and this is mainly because the government seems to deny the uncertainties that exist about the HPV-vaccination.

It is interesting to see that the government does acknowledge that they made mistakes in their communication with the public. They state that they treated the HPV-vaccine as a classic vaccine, by which they mean that the tenor of their message to the public was that the vaccine is good for them and that all the girls should get vaccinated, just like with the other vaccines in the National Vaccination Program. This corresponds with the critique of the anti-vaccination movements about the government being too positive about the vaccine. To improve their communication the government changed the tenor of their message to being more informative and letting the public make their own choice.

### **IMPLICATIONS**

There is a task for the government in improving their communication. The results show that the government is already critical about the way they communicated with the public; they recognized that their first message was too paternalistic, or what anti-vaccination movements called “too one-sided positive”. But the government can still improve their communication.

In the first place the government should be open about the uncertainties that exist about the efficacy and side-effects of the HPV-vaccine. An example of such an uncertainty is that it will take

years before it can be concluded with absolute certainty that the vaccine indeed prevents cervical cancer. According to Wynne (2006) experts have to show to the public that they are trustworthy in order for the public to listen to them. He advises experts to be open and honest about uncertainties and unpredicted consequences and show the public what is done to monitor the side effects and how possible negative effects will be managed if they emerge. This last recommendation is already partly implemented by the government, because on their website they give insight in all reported side effects of the vaccine.

Secondly, the government should be wary to dismiss opposition as spreading “old wives’ tales”. Maybe the stories told by the opposition are actually not fully based on facts. However, this should not be a reason for the government to completely stop listening to what these stakeholders have to say and to just keep on hammering on their scientific side of the story. People always have a valid reason when they decide not to get vaccinated, whether they base their decision on science, on emotions, or a combination of both. The fact that the government bases her decisions on science does not mean the public does this as well. By dismissing some of the reasons people have not to get vaccinated as nonsense, this only adds to the skepticism that may already exist among the public.

A final implication for the government is that they should try to avoid every possible appearance of a conflict of interests by scaling back the ties with the industry, as Shapin (2004) suggests. However, since almost every scientific expert can be linked to industry in some way these days, it will be important to be open about the links that exist and to make the decision-making process transparent, as Wynne (2006) suggests. Conflicting interests stand in the way of the government coming across as having good intentions and thus in people trusting the government to decide what is best for them. The appearance of conflicting interests is easily fed by anti-vaccination movements, so the government should be completely transparent about the ties with industry that might exist within their organization.

### **5.1.3 COMMUNICATION BY THE PHARMACEUTICAL INDUSTRY CAUSED UNREST ABOUT THE HPV-VACCINATION**

Nearly all respondents point to the pharmaceutical industry as playing a role in causing the discussion about the HPV-vaccination. Although vaccine producers are not allowed to advertise about a vaccine, they are allowed to raise awareness about a disease. They tried to raise such awareness through radio and TV commercials and through articles about cervical cancer in magazines. Many stakeholders construct this campaign as having caused unrest among the public and having a negative effect on the communication by the government. This negative effect was said to be caused by the negative image of the pharmaceutical industry that already exists among the public in combination with the government communicating a message that corresponded with the campaign of the industry: protect your daughter, go get her vaccinated.

This way it seemed the government and the industry had the same goal and therefore also the same interests.

Although the representatives of the pharmaceutical industry do acknowledge that the other stakeholders accuse them of playing a negative role, they are not very critical of themselves. They more or less say they are doing their job and that's just the way things work. They point to the government for failing to communicate properly with the public.

Looking back at the literature Shapin (2004) advocated a scaling down of the ties between experts and the industries. He notes that the appearance of conflicting interests does damage to the good intentions of experts. Wynne (2006) also advises experts to be transparent about their ties with the industries in order to show trustworthiness. It seems that in this case the appearance of conflicting interest played a role and indeed did damage to the trustworthiness of the government.

#### IMPLICATIONS

The first implication corresponds to the last implication of the previous section. Following the advice of Shapin and Wynne the government, and scientific experts working for the government, should try to scale back the ties they have with the industries and be transparent about the ties that remain. Where possible the government should use experts who are free of any ties such that the appearance of conflicting interests is diminished. This would probably not take away all suspicion that exists among the public. Some members of the public, such as the representative of the distressed mothers' website, are convinced that financial interests are at the basis of every vaccination. As a result these members of the public will reject any form of authority.

The conclusions drawn here also have implications for the pharmaceutical industry. One of the results of the interviews is that the vaccine producers do not seem to be very critical about their own role in the discussion. They view their own actions as the way things normally go and do not agree with the critique that is expressed by other stakeholders. Even if they believe they played no part in causing the discussion, it is still in their own interest to make sure that scientists that perform research for the industry, and members of the Health Council, do not appear to be under the influence of conflicting interests.

The mere fact that almost all other respondents point to the role of the pharmaceutical industry in causing unrest among the public, should be enough indication that self-reflection could be useful. The marketing campaign the industry held with the purpose of raising the public awareness of cervical cancer led to a lot of skepticism, and not only among anti-vaccination movements. Therefore the next time a case like the HPV-vaccination might occur, the vaccine producers should reconsider the way they approached the situation in the case of the HPV-vaccination.

Some of the stakeholders are of the opinion that the pharmaceutical industry made the task of the government difficult, because they were sending the same message as the government, which was that the vaccine was a good thing. Therefore next time it can be useful for the vaccine producers to adapt their communication to that of the government.

#### **5.1.4 ONLY GOVERNMENT REPRESENTATIVES IDENTIFY A DECLINE OF SCIENTIFIC AUTHORITY TO DESCRIBE THE DIMINISHING OF THE SELF-EVIDENT AUTHORITY OF SCIENTIFIC EXPERTS**

One of the aims of this research was to find out what role scientific authority played in a case where it seemed to be in decline and which stakeholders defined the problem as such. In the first place it can be concluded that there is no consensus about what the term “scientific authority” means. In section 2.1 scientific authority was defined as the public accepting the advice or decisions of scientific experts and viewing them as legitimate. Some respondents indeed define scientific authority as having the public act on the advice of scientific experts, while others define it as the public listening to scientific experts because they are an expert, whether they agree with them or act on their advice or not. Most respondents had difficulties giving a definition of scientific authority, but they did associate it with trustworthiness, credibility and independency. Looking back at the definition these terms can be viewed as supposed conditions for a scientific expert in order to have authority.

Apparently it is not clear at all what is understood with the term scientific authority. This result raises the question what is meant when experts publicly speak of a decline in authority. The representatives of the government do identify a decline of this authority, but they are not able to exactly describe where they get this idea from. One example mentioned by a representative of the Ministry of Health is that the opinion of a former nurse is valued as equal to the opinion of a group of experts. By mentioning this example with regard to a decline of authority, the respondent constructs the nurse as competing with the experts for authority, instead of viewing her as a full participant in the same discussion.

This example corresponds with the presumption of Dijstelbloem and Hagendijk (2011), who think that it is the diminishing of *self-evident* authority that public experts complain about. These experts expect the public to value the opinion of a renowned scientist higher than that of what they feel is a lay person. The finding that the representatives of the government speak of a decline of authority shows that they do expect the public to listen to them. By defining this decline they implicitly lay the cause for the discussion at the side of the public, who should go back to listening to what experts tell them.

Another difficulty that came up when trying to define a decline of scientific authority is the fact that scientific experts are working for, or publicly speaking in name of, the government. This makes it difficult to determine if a possibly observed decline of authority has to be attributed to

the scientific experts, or to the government in name of which the expert speaks. Several respondents rather speak of a decline of trust in the government than of a decline of scientific authority.

The finding that authority is associated with trust, credibility and independency is in line with the reasoning of Wynne (2006). Wynne states that experts should not think of the public as having deficits in knowledge or trust when they are having troubles with getting their message across, but they should look at their own trustworthiness. In a way this also corresponds with what Shapin (2007) calls the “good intentions” of scientists; in order for people to trust someone they have to be convinced of their good intentions. Experts that seem to act under influence of the pharmaceutical industry do not come across as acting in the best interest of the public. In order to have people trusting them it is important for scientific experts to show their good intentioned. In the case of the HPV-vaccination this means the personal concerns of the public should be addressed in the communication and scientists should go against the apparent and show that they are free of conflicting interests.

Anti-vaccination movements describe scientific authority as a negative thing. Or to be more precise, they feel that the government and the scientific experts are trying to use authority to influence the public with their “unfunded pro-vaccination propaganda” as one of the respondents described it. This corresponds with what Myers (2004) describes as public experts using their expertise to claim the entitlement to speak, Myers argues that people who object expert communication often object this claim instead of the correctness of the content of the message. Furthermore the people who do rely on the authority of the government are dismissed as “sheep that follow one another without thinking for themselves”. This is exactly as described by Hobson-West in her article on the organized resistance to childhood vaccination in the UK (Hobson-West, 2007). Hobson-West also argues that the public has to take a leap of faith in trusting the government and in the discussion about the HPV-vaccination a substantial part of the public seems not to have been willing to take that leap.

#### IMPLICATIONS

When it comes to the understanding of scientific authority the most striking result is that the respondents have difficulties in defining what it is exactly and in defining how a possible decline becomes visible. One of the reasons could be that the term is used strategically: practically everyone will agree that a scientist has more knowledge about his own area of expertise than a lay person. By defining the issue as an authority problem, a scientist can try to use this natural matter of course to reclaim his entitlement to speak, setting aside all other aspects that play a role. However it remains the question is defining the issue as such contributes to a fruitful discussion. One of the most important implications is therefore that it is time to start a discussion about what is understood by scientific authority and what is expected of scientific authority in cases like the introduction of the HPV-vaccination. If the people, who claim that the

authority of science is waning, mean that the public does not simply do as experts tell them to do, then it might be useful to think about whether that is the desired state of affairs. If this last question is answered negatively then is a decline of scientific authority even something to be surprised or worried about? It could also be the logical consequence of the public becoming more active in public debate; the public talking back to the scientific experts seems incompatible with the public doing exactly as experts tell them to do. Although these last remarks are speculative they do show that it will be useful to discuss what is understood with scientific authority and what is the desired situation when scientific experts participate in a public discussion. Setting up such a discussion ideally is a task for science communicators, who are experts on the role of science in society and can identify themselves with both the public experts and the public.

The fact that the anti-vaccination movements frame scientific authority as a negative thing is also an indication that it is not a good thing for experts to simply rely on authority to get their message across. Hobson-West (2007) explains the public can feel they have to take a leap of faith when it comes to making decisions about topics like getting vaccinated or not. It should be the goal of the government and the scientific experts who work for the government to build trustworthiness and to make sure this leap of faith is diminished to a small hop. They can establish this by providing all the information the public needs to make an informed choice and by being open and honest about risks and uncertainties (Blume, 2006). Furthermore the government has to acknowledge that the citizens have the right to make their own choice, so in the communication the tenor should be avoided that it is stupid not to get vaccinated.

## **5.2 LIMITATIONS**

In the method chapter already a number of limitations of the method for this research were listed.

One of the main limitations of this research is that it is a single case study. The findings of this study are based on the discussion about a vaccine and it might well be that in other cases where scientific authority seems to be in decline, other results are obtained. It is therefore difficult to generalize the results presented in this chapter. The results however do show that there is ground to be gained in the relation between scientific experts, the government and the public and this is probably not only the case for health care issues.

Another limitation of this research is that the role of the media has been underexposed. The broadcast of Zembla was mentioned by several respondents as playing an important role in the discussion and it would have been interesting to see how the makers of the program constructed the discussion and what their reasoning was behind the way they framed the discussion in their show. Media appear to have no interests in terms of being pro- or anti-vaccination, their main

interests are probably aspects such as drama or finding newsworthiness, so their view on the discussion could have led to other insights.

During the study only ten interviews were conducted and this forms also a limitation. This fact in combination with the observation that some stakeholder groups being represented by only one respondent leads to some question marks about the validity of the research. Interviewing different and more respondents could have led to different results. In defense of the current research it has to be said that the views of stakeholders who belong to the same stakeholders group, such as the two anti-vaccination movements or the representatives of the ministry of VWS and the RIVM who both work for the government, seem to correspond to a large extent.

A final limitation of the current research lies in the fact that the interviews were held and analyzed by only one person. Ten interviews of one hour lead to such an amount of data that relatively only a small part ended up in the results chapter. Therefore it could well be possible that a different person analyzing the data could come up with slightly different results..

### **5.3 RECOMMENDATIONS FOR FURTHER RESEARCH**

The findings of this research give way to several new questions about scientific authority and the role of scientific experts.

One of the implications discussed in this chapter is the start of a discussion about what is expected of scientific authority and the role of science and scientific experts in public discussions. An outline for such a discussion can be formed by an investigation under public experts to find out what they understand by the term scientific authority, to what extent they assume they possess authority themselves and how they feel the state of affairs, with respect to the role of science and scientific experts, should be in a case like the HPV-vaccination. The outcomes of such a study could form the input for a discussion between these same public experts and members of the public, by comparing the ideas of the experts with the demands of the public. A difficulty that has to be overcome is defining who 'the public' is in this case and therefore it's probably best to limit such a discussion to a specific case in which the different stakeholders can be identified, such as the case of the HPV-vaccination. The discussion should be about what is expected from scientific experts and what should be the proper way for them to approach the public in a public discussion. As mentioned before science communicators seem to fit the role of setting up such a discussion, because they are able to understand the views of the experts as well as the view of the public.

Another implication of the current research is that public experts should work on building trustworthiness when they are involved in a public discussion. It will be interesting to find out to what extent public experts think the public already sees them as trustworthy and what they think they can do to improve this trustworthiness. The results of such a study are of course of



value to the public experts themselves as it will show where there is still ground to be gained when it comes to trustworthiness. Besides such a study may also lead to insights in the way in which public experts define their own role in a public discussion and to what extent they are willing to change their doings in order to build trustworthiness.

A result of the current research is an overview of causes for the discussion about the HPV-vaccination, as constructed by the stakeholders in the discussion. This overview should not be confused with the reasons that members of the public may have had to decide not to get vaccinated. A study of the motives that these members of the public had for their decisions will lead to more insight in the grounds on which members of the public make decisions about topics like vaccination. These insights could prove to be valuable for government communication and the role of public experts in this communication.



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## **A. INTERVIEW GUIDE (DUTCH)**

### **INTERVIEWSCHEMA**

Interview HPV-vaccinatie

**Respondent:** [REDACTED]

**Datum interview:** 14 februari 2012

**Locatie:** Ministerie VWS – Den Haag

**Geïnteresseerd in eindrapportage:** Ja/Nee

#### **Voor het interview de volgende punten onder de aandacht brengen**

- Onderzoek in kader van afstudeeropdracht aan de Universiteit Twente
- Doel van het interview: inzicht krijgen in aspecten die een rol gespeeld hebben in de discussie rondom de invoering van de HPV-vaccinatie. Dit wordt gedaan door de discussie te bekijken vanuit het oogpunt van verschillende betrokkenen bij de discussie
- De respondent is gevraagd deel te nemen, omdat hij of zij een rol heeft gespeeld in de discussie rondom de invoering van de HPV-vaccinatie
- De vragen zullen vooral gaan over de aard van de discussie, en de rol die de respondent en andere betrokkenen gespeeld hebben
- Vragen worden gesteld aan de hand van een interviewschema, daardoor kan het voorkomen dat een enkele vraag misschien al impliciet een keer beantwoord is bij een eerdere vraag, sommige punten lijken misschien naar de bekende weg te vragen. Vriendelijk verzoek om de vraag toch te beantwoorden
- Interviewschema kan er ook voor zorgen dat ik soms even moet controleren of ik alle informatie heb die ik nodig heb
- Eind maart wordt het onderzoek afgerond, eindverslag kan opgestuurd worden (evt. digitaal)
- Geluidsopname van het interview is nodig, in verband met de analyse. Opname wordt alleen door mij beluisterd en wordt uitsluitend voor het huidige onderzoek gebruikt
- Interview duurt ongeveer een uur
- Heeft de respondent verder nog vragen of opmerkingen?

Tijdstip begin: \_\_\_\_: \_\_\_\_

Standaard doorvragingen:

- Waaruit blijkt dit volgens u?
- Kunt u een voorbeeld geven?
- Had u daar zelf mee te maken?
- Kunt u dat omschrijven?

## **VRAAG 1 – DEFINITIE DISCUSSIE**

*Hoe is de discussie rondom de HPV-vaccinatie volgens u tot stand gekomen?*

- *Wat is volgens u de reden geweest voor de onrust?*
- *Waarom was de opkomst voor de vaccinatie volgens u zo laag?*

Chronologische weergave van de discussie is niet belangrijk, het gaat erom hoe de respondent de discussie over de HPV-vaccinatie definieert. Zelf zo min mogelijk over die discussie zeggen.

## **VRAAG 2 – DOELEN**

*Hoe raakte het Ministerie bij de discussie betrokken?*

- *Welke rol speelt het Ministerie in zo'n discussie?*
- *Waarom denkt u dat er zo op uw acties gereageerd werd?*
- *Wat vond u daarvan?*
- *Hoe hebt daar zelf weer op gereageerd?*
- *Is er nog vanuit andere hoeken op u gereageerd?*
- *Welke redenen heeft u hiervoor?*

Het gaat er hierbij om dat de positie van de respondent in de discussie duidelijk wordt. Welke motieven had de respondent om deel te nemen aan de discussie. Geen voorbeelden van mogelijke motieven geven.

### **VRAAG 3 – RELATIES**

*In de discussie zijn verschillende partijen te onderscheiden, zoals wetenschappers, de overheid, de industrie, media en burgers.*

Per partij de vragen stellen, niet eerst allemaal noemen. Het is belangrijk dat duidelijk wordt hoe de respondent tegen andere betrokkenen aankijkt en wat hij van deze andere betrokkenen vindt. Wetenschappelijke experts worden later behandeld.

**Overheid-** *Hoe verloopt het proces van het invoeren van een vaccinatie?*

- *Wanneer had u door dat het een discussie opleverde?*
- *Heeft u veel te maken gehad met kamerleden?*
- *Welke rol heeft de overheid volgens u in de discussie gespeeld?*
- *Waaruit blijkt dat?*

### **Farmaceutische industrie**

- *Welke rol heeft de farmaceutische industrie volgens u in de gespeeld in discussie gespeeld?*
- *Wat vond u van de marketing-strategieën van de industrie?*
- *Wat vind u van het feit dat de farmaceutische industrie veel onderzoeken betaalt?*

### **Media**

- *Welke rol hebben media volgens u in de discussie gespeeld?*
- *Wat vond u daarvan?*

**Burgers –** *Heeft u met de bezorgde moeders te maken gehad?*

- *Wat vindt u van de anti-vaccinatie bewegingen?*
- *Heeft u daar contact mee?*
- *Heeft het Ministerie contact met burgers?*

#### **VRAAG 4 – STANDPUNT**

*In november van 2008 besloot de Minister op advies van de Gezondheidsraad om de HPV-vaccinatie in het Rijksvaccinatieprogramma op te nemen. Wat vond u van het besluit om de HPV-vaccinatie landelijk in te voeren?*

- *Welke redenen had u om het eens of oneens te zijn met het besluit om de HPV-vaccinatie in te voeren?*

De mening van de respondent betreffende de invoering van het vaccin moet achterhaald worden, alsmede de motieven die hij heeft voor deze mening. Verder moet duidelijk worden hoe de mening van de respondent zijn acties in de discussie beïnvloed heeft.



## **VRAAG 5 – ROL WETENSCHAPPELIJKE INFORMATIE**

*Welke rol heeft wetenschappelijke informatie volgens u gespeeld in de discussie rondom de HPV-vaccinatie?*

- *Over welke onderwerpen was er wetenschappelijke informatie beschikbaar?*
- *Waren er redenen om te twijfelen aan de juistheid van de wetenschappelijke informatie?*
- *Waaruit bleek dat?*
- *Waren er redenen om te twijfelen aan de juistheid van het advies van de Gezondheidsraad?*
- *Waaruit bleek dat?*

Het doel van de vraag is om de respondent de positie van wetenschappelijke informatie in de discussie te laten bepalen. Hieruit kan blijken hoe de respondent tegen wetenschap aankijkt en welke problemen hij ziet voor de rol van wetenschap in de discussie.

## **VRAAG 6 – ROL WETENSCHAPPELIJKE EXPERTS**

*Heeft u te maken gehad met wetenschappelijke experts?*

- *Hoe verliep dit contact?*
- *Welke rol hebben wetenschappers volgens u gespeeld in de discussie?*
- *Welke houding nemen wetenschappelijke experts aan tijdens een discussie?*
- *Hoeveel waarde moet er volgens u gehecht worden aan het advies van wetenschappelijke experts en waarom? Wanneer wel en wanneer niet?*
- *Hoe moet de overheid omgaan met wetenschappers die het openlijk niet met elkaar eens zijn? En hoe moeten burgers daar mee omgaan?*

Uit deze vraag moet blijken hoe de respondent tegen wetenschappelijke experts aankijkt.

### **VRAAG 7 – DEFINITIE WETENSCHAPPELIJKE AUTORITEIT**

*Er wordt gezegd dat het gezag van wetenschap in het gedrang is. Wat verstaat u onder wetenschappelijk gezag?*

- *Vindt u het een goede zaak dat wetenschap wel/geen gezag heeft ?*
- *Kunt u een voorbeeld geven waarom dit wel/niet goed is?*

Het begrip wetenschappelijke autoriteit is niet eenduidig, daarom is het belangrijk te achterhalen wat de respondent eronder verstaat, voordat hij er vragen over kan beantwoorden.

### **VRAAG 8 – AFNAME WETENSCHAPPELIJKE AUTORITEIT MBT HPV**

*Heeft u het idee dat het gezag van wetenschappelijke in het gedrang was bij de discussie rondom de HPV-vaccinatie?*

- *Waaruit blijkt die afname van autoriteit? Kunt u voorbeelden noemen?*
- *Heeft u het idee dat de autoriteit van de overheid afneemt?*
- *Waaruit blijkt dat er wél sprake van autoriteit is? Kunt u voorbeelden noemen?*
- *Waar ligt dit aan?*
- *Welke rol speelt wetenschappelijke autoriteit in de discussie rondom de HPV-vaccinatie?*
- *Heeft u zelf het gevoel dat wetenschappers over autoriteit beschikken?*
- *Kunt u hier een voorbeeld van geven?*
- *Ervaart u zelf een afname van autoriteit?*

Ervaart de respondent een afname van autoriteit van wetenschap? Niet tevreden zijn met een “Nee” als antwoord. Proberen door te vragen zonder zelf voorbeeld aspecten te noemen waaruit een afname kan blijken.

## **VRAAG 9 – OPLOSSINGEN**

*Wat moeten wetenschappers doen om dit soort discussies te voorkomen?*

- *Welke rol zou wetenschap volgens u moeten spelen in een discussie zoals die rondom de HPV-vaccinatie?*
- *Hoe zou er gecommuniceerd moeten worden over wetenschappelijk onderzoek in een discussie als deze?*
- *Tot in hoeverre moeten wetenschappelijke experts zich mengen in een discussie als deze?*
- *Had de hele discussie voorkomen kunnen worden? Hoe?*

Het doel van deze vraag is achterhalen welke rol wetenschap volgens de respondent moet spelen en hoe wetenschappelijke experts deze rol kunnen vervullen.

Tijdstip eind: \_\_\_\_: \_\_\_\_

### **Na het interview**

- Afsluiten, dit was de laatste vraag
- Vragen of de respondent nog opmerkingen of toevoegingen heeft
- Bedanken



## **B. OVERVIEW INTERVIEWS**

| <b>Date</b> | <b>Respondent</b>   | <b>Location</b> |
|-------------|---|-----------------|
| 12-12-2011  | One of the authors of the critical article on the Health Council advise (de Kok, et al., 2008)                              | Rotterdam       |
| 22-12-2011  | Member of the Health Council committee that formed an advice on the HPV-vaccination and Professor of Oncological Gynecology | Amsterdam       |
| 22-12-2011  | Science journalist with columns in national newspapers and critical of the Health Council advice                            | Amsterdam       |
| 10-01-2012  | Representative of the distressed mothers' website   | <i>Skype</i>    |
| 17-01-2012  | National Immunization Program manager at the RIVM   | Bilthoven       |
| 19-01-2012  | Representative of the Association of Critical Jabbing   | <i>Skype</i>    |
| 01-02-2012  | Commercial Director Vaccins at Glaxo Smith Kline  | Zeist           |
| 14-02-2012  | Head of department of Crisis control and Infectious Diseases at the Ministry of VWS   | The Hague       |
| 14-02-2012  | Former head of Public Affairs and Communication at Sanofi MSD   | Amsterdam       |
| 16-03-2012  | Gynecologist openly in favor of the HPV-vaccination   | Groningen       |



## C. ORIGINAL INTERVIEW FRAGMENTS

- 1) **I:** Hoe is de discussie over de invoering van de HPV-vaccinatie volgens u tot stand gekomen?
- Pha1:** [...] Heb je het nu over de discussie die ontstond vóór de invoering, of de discussie die ontstond ná de invoering. Je zegt óver de invoering.
- I:** Ja, waar denkt u het eerste aan?
- Pha1:** Ja, er zijn twee discussies gevoerd, er zijn er wel meer gevoerd.
- I:** Ok, dan noemt u ze beide.
- Pha1:** Nou in eerste instantie denk ik, vóór de invoering, zijn er een aantal wetenschappers geweest die vonden de informatie, wetenschappelijk kennis, die verzameld was, om tot een besluit te komen [...] onvoldoende en ze hadden heel erg de behoefte om zelf daar nader onderzoek naar te verrichten. [...] Dat was de eerste discussie. Die discussie sloeg daarna over, van de wetenschappers naar mensen die meer in het algemene publiek zitten.

- 2) **I:** Op een gegeven moment is de discussie veel groter geworden, door een hele hoop verschillende omstandigheden.
- ScJo:** Ja.
- I:** Waar ging het toen over denkt u? Op een gegeven moment is het advies gegeven, van de Gezondheidsraad, de Minister heeft besloten om het in te voeren en toen brak er een hele discussie uit, waar heel veel mensen bij betrokken zijn geweest.
- ScJo:** Ja, maar de discussie borrelde al veel langer. Kijk, eigenlijk was de beslissing van de Minister om het in te voeren op gezag van de Gezondheidsraad [...] het einde van de discussie. Toen, ja, toen was de wetenschappelijk discussie in ieder geval een beetje voorbij.

- 3) **I:** Welke rol heeft wetenschappelijke informatie volgens u gespeeld in de discussie?
- Pha2:** Ja, in de maatschappelijke discussie weinig. Te weinig. In de echte discussie zeg maar, onder diegene ja, die bepalen, onder de Gezondheidsraad en het RIVM, heel veel. Ik denk dat dat, daar is echt op basis van pure feiten gekeken. En in het maatschappelijke debat ging het echt over opinies die niet, die echt niet door feiten gestaafd zijn. Dat ging over opinies van mensen, die tegenover elkaar gezet werden en niet over de feiten. [...] dus het debat, zeg maar, in de publieksmedia, was anders dan het debat binnen de experts [...].

- 4) **I:** Welke rol hebben wetenschappers gespeeld nadat het advies gegeven was? Hebben ze toen nog met de discussie bemoeid?
- CrRe:** Nou ik had toen heel erg zoiets van, nou, het is ingevoerd, nou is het ook klaar. Dat, daar ga ik niet nou dan nog tegenaan lopen schoppen, dat, het is nu een gegeven, ja, dan moeten we daar ook geen discussie meer over gaan voeren.[...] ik wilde gewoon één keer dat geluid laten horen, dat tegengeluid, en dan, dat was mijn doel. Dat er ook eens een keer dat, de andere kant van het verhaal gehoord werd en [...] er bleven ook maar mensen komen van, wil je nog een keer in dat tijdschrift en daar, en na een tijdje had ik zoiets van nou is het klaar weet je wel. De discussie is gevoerd, het is ingevoerd en nou moeten we maar gewoon het beste er van maken en maar hopen dat we geen gelijk hadden, dat, ja.

5) **I:** En waarom denkt u dan, dat ondanks die onzekerheden [over de (bij)werkingen van het vaccin], toch het advies gegeven is om het wél te doen?

**ScJo:** Dat weet ik niet. Ik bedoel, dat ligt in de schoot van de Gezondheidsraad. [...] Het probleem is, je hebt screeners en je hebt virologen. Screeners die zeggen, ja maar, zoveel inspanningen voor één voorkomen sterfgeval, is dat wel de moeite wel waard. En je hebt virologen en vaccinologen, zoals Roel Coutinho [directeur van het Centrum Infectieziektebestrijding bij het RIVM], die zeggen, ja maar er is een vaccin wat kanker kan voorkomen, is dat niet prachtig, moeten we dat niet invoeren? Dus die zijn op een heel andere manier enthousiast daarover. En ik denk dat die partij binnen de Gezondheidsraad gewonnen heeft.

6) **I:** En wat, wat is dan het grootste discussiepunt? Of is dat niet openbaar?

**HeCo:** Het zijn eigenlijk al die punten [die in het rapport van de Gezondheidsraad staan] ja. Kijk en, als je zelf, en dat is denk ik een van de dingen waar die epidemiologen over gevallen zijn, als je heel erg vanuit de oncologie kijkt naar het gezondheidsprobleem, dan zijn 250 doden per jaar, nouja, daar maakt niet iedereen zich zo vreselijk druk over. Maar als je kijkt naar bijvoorbeeld vanuit vaccinatiedeskundigen, die zeggen als je 100 doden per jaar kan voorkomen door een mooi preventief middel op jonge leeftijd, dat is een hartstikke goed succes. Want met de mazelenvaccinatie voorkomen we ook, misschien 30 doden per jaar of 10 doden per jaar.

7) **I:** Waarom is het advies dan toch gegeven, denkt u? [...]

**CrRe:** Ik weet dat er toen de discussie was, de voorzitter van de Gezondheidsraad, die vond niet dat je die 200 doden, of die 100 doden per jaar, die je dan zou winnen, dat, hij zei dan, wie zijn wij om dan te zeggen dat je dat niet mag invoeren, voor die 100 vrouwen. Nouja, zij waren natuurlijk precies de instelling die dat kon zeggen [...].

8) **I:** Dus u had het idee dat bij de Gezondheidsraad, die wilden echt kiezen tussen of een ja of een nee en niet-

**CrRe:** Ja, nouja, die vonden toch die 100 doden, dat vonden ze toch wel heel erg zwaar wegen. Is natuurlijk ook wel zo, maar je wist niet wat er tegenover stond. Als je aan negatieve en aan hoge kosten [denkt] en ja. Je had ook kunnen zeggen van nou we doen het niet en we gaan zorgen dat de mensen beter naar het bevolkingsonderzoek komen en dan had je misschien ook wel die 100 doden gewonnen.

9) **I:** Hoe is de discussie over de invoering van de HPV-vaccinatie volgens u tot stand gekomen?

**DiMo:** Nou die is tot stand gekomen omdat wij, dus, de andere kant, de anders denkenden, daarmee naar buiten kwamen. Ik zal je vertellen hoe ik ben begonnen, dat is misschien ook wel interessant. In 2008, toen, nouja, toen verscheen er dan in de media, kopje in de krant, stukje op de televisie, hè, zo in de zomer en het najaar, dat dat vaccin eraan zat te komen, het werd gepromoot in feite al. En elke keer als ik dat zag, dan was mijn gedachte, mijn gevoel, nou dat kan niet waar zijn. Krijgen we straks een vaccin tegen maagkanker, tegen leverkanker, of krijgen we een cocktail.

10) **I:** In het begin noemde... U omschreef uzelf als "andersdenkende".



**DiMo:** Kijk het RIVM en anderen van de overheid en de laboranten, virologen, noem het allemaal op, die de vaccinaties promoten, die zijn er natuurlijk heilig van overtuigd... of ze vertellen het vanuit hun "moeten", want ja, of ze zelf diep van binnen overtuigd zijn is ook maar de vraag. Maar ja, die promoten het hevig, wij zijn degenen die zeggen, hé, wordt wakker, er is ook een andere kant.

11) **I:** Ok, ja, dus als ik het goed begrijp is de informatie [waarin de nut van het vaccin in twijfel wordt getrokken] die u gegeven hebt...

**NVKP:** ...correct en juist!

**I:** Ja, precies. Maar tóch is dat advies gegeven door de Gezondheidsraad.

**NVKP:** Ja, belachelijk niet? Het is toch niet te geloven! [...] Het advies heet "Vaccinatie tegen baarmoederhalskanker". Dat vind ik dus al de eerste blunder die de Gezondheidsraad maakt. Het is namelijk helemaal geen vaccinatie tegen baarmoederhalskanker. Dit is wéér het beïnvloeden van mensen die er geen verstand van hebben. Het is een vaccinatie tegen een HPV-infectie, die in zéér uitzonderlijke gevallen aanleiding zou kunnen zijn tot baarmoederhalskanker. Dat moeten we nog maar afwachten, dat is wat ze denken dat het is, maar het is dus geen vaccinatie tegen baarmoederhalskanker. Nou tegen dit soort dingen, daar maken wij dus bezwaar tegen. Die eenzijdige, positieve, ongefundeerde, propaganda voor zo'n vaccin.

12) **I:** Waar in de tijdslijn plaatst u dat, dat u daarmee [het HPV-dossier] begon?

**NVKP:** Dat zal in 2007 zijn geweest, 2008? Daar omtrent.

**I:** Ja, ok, dus nog voordat de Gezondheidsraad met een advies kwam.

**NVKP:** Ja, want, toen wij dus dat rapport afgerond hadden toen, en opgestuurd hadden, toen is dat voor de Gezondheidsraad, is dat een reden geweest om ons uit te nodigen om daarover te komen praten. En dat kan je ook zien want in het eindrapport wat de Gezondheidsraad heeft opgeleverd aan de Minister, daar staan wij vermeld. Nou dat is dus een start geweest van, iets dat uiteindelijk dus groter en groter is geworden. [...]

13) **NVKP:** Normaal is het zo dat wij leveren informatie aan, zodat ouders, in de meeste gevallen zijn het ouders, zelf de beslissing kunnen nemen, doe ik dat vaccin wel, doe ik het vaccin niet. Wij geven daar geen advies bij. Bij het HPV-vaccin hebben we dat dus wel gedaan, voor het eerst, dat we hebben gezegd van, meiden, dat moet je niet doen. Nou, en, dat stond ook in het dossier, daar zijn dus een aantal zaken mee aan de haal gegaan en dat is groter en groter geworden en, ja, op een zeker moment krijg je dan dus de nationale discussie zal ik maar zeggen, hè.

14) **I:** Neemt u dat [negatieve informatie uitvergroten] hen [journalisten] dan ook kwalijk?

**RIVM:** Ja, dat is koppenschrijven. Een journalist kan nog zo genuanceerd zijn, maar dat kan ehm... Dit heeft natuurlijk wel grote effecten, ik bedoel, ik, ja, ik vind dat mensen wel hun verantwoordelijkheid [hebben] in wat ze neer[zetten]... Niet dat ik enige illusie heb dat je dat in de hand kunt houden, wij hebben vervolgens de taak om al die geluiden, om daar een antwoord op te geven. Dat kan ik ons ook kwalijk nemen dat wij daar in eerste instantie niet goed in geslaagd zijn.

15) **I:** En wat is dat het doel wat je wilt bereiken met zo'n gesprek [van een vertegenwoordiger van de overheid in de media]?

**VWS1:** Dat is een leuke, daar hebben wij het toevallig net over gehad [...] En daar raak je wel een punt waar we ook wel over in discussie zijn, het doel van onze strategie is informatie leveren over de

maatregelen die een burger kan nemen, en die je als overheid ook aanbiedt, ter bescherming van infectieziekten. [...] En ik denk, dan komen we meteen alweer op een volgende vraag, ik denk, terugkijkend, dat we daar niet heel expliciet over gecommuniceerd hebben, van wat is nou precies het doel van onze boodschap, het was toch vooral van: het is goed voor je.

16) **I:** En wat voor een effect heeft dat gehad, denkt u?

**VWS1:** Ja, ik denk dat er heel veel dingen met elkaar samenhangen. Wat Philip [respondent VWS2] eerder zei, het is een heel apart vaccin, voor een aparte leeftijdscategorie, een moeilijke leeftijdscategorie, en ook nog eens voor mogelijke effecten op de lange termijn. En ook nog eens gerelateerd aan seksueel gedrag. Dus dat was een hele aparte setting, maar daarbij denk ik [...] straalde de overheid aan de ene kant uit wel uit: jij moet het besluit nemen, maar je bent dom als je het besluit neemt om je kind niet te vaccineren. Terwijl in de tweede ronde de boodschap veel meer was, van goh, wij willen het aanbieden, voor wie het wil, en we willen alle informatie beschikbaar stellen, dus daar zit een iets andere teneur in.

17) **I:** Hoe raakte u zelf bij de discussie betrokken?

**CrRe:** [...] Wij [hebben] met een groepje een stuk geschreven in het Nederlands Tijdschrift voor Geneeskunde, omdat we ons afvroegen of het wel de juiste tijd was om het al in te voeren, voor de hele populatie. En zeker omdat wij hadden destijds het gevoel hadden dat er eigenlijk alleen maar positieve geluiden waren en zeker ook binnen die Gezondheidsraad wisten we wel dat er ook negatieve geluiden waren, maar naar buiten toe werden eigenlijk alleen maar positieve geluiden verspreid. Dus wij vonden dat het een beetje genuanceerd moest worden en ook eens een keer de andere kant van het verhaal, wat wel bekend was. Onder de experts was dat wel bekend, maar wij vonden met dat groepje dat het eigenlijk ook wel naar de algemene populatie gefilterd mocht worden.

18) **I:** Kunt u omschrijven hoe de discussie rondom de HPV-vaccinatie volgens u tot stand is gekomen?

**RIVM:** [...] Het artikel in het Tijdschrift voor Geneeskunde [...] waarin ze [de kritische onderzoekers] hun mening geven over deze HPV-vaccinatie, heeft natuurlijk ook een grote rol gespeeld. Zij zeiden: het is te vroeg voor die vaccinatie, het is geen urgent volksgezondheidsprobleem. [...] Het bericht wat deze mensen, die dus binnen de Gezondheidsraad al hun visie hadden gegeven, en dat vervolgens hebben gepubliceerd, dat is een beetje een eigen leven gaan leiden, want dan wordt er gezegd van: zelfs de geleerden vinden dat het te vroeg is. Dat heeft een rol gespeeld.

**I:** Neemt u hen dat kwalijk?

**RIVM:** Ik vind dat ze daarin echt behoedzamer had moeten zijn. [...] Het heeft toch een grote impact gehad, als je ziet dat dan iedereen zegt: ja zie je, het is helemaal niet alleen maar een hyperig iets of een complottheorie, of wat dan ook, nee, ook wetenschappers vinden dat we het niet moeten doen. Dat heeft denk ik een grote rol gespeeld.

19) **I:** Dus als ze [de kritische wetenschappers] dat [onderzoek naar de werking van het vaccin] zelf hadden uitgevoerd, dan hadden ze dat [resultaat] positiever geïnterpreteerd?

**Pha1:** Ja, want wat ze nu deden [...] [is] een heleboel vragen stellen, wat een onderzoeker denk ik gelegitimeerd is om te doen, maar op het moment dat je je als onderzoeker in de algemene media gaat begeven en je stelt dan die vragen die je eigenlijk, nouja, onder onderzoekers, onder elkaar zou willen stellen, dan hebben die, op zich terechte vragen, die hebben een hele andere uitwerking.

**I:** Ja, namelijk...?

**Pha1:** Ja namelijk, [...] een journalist die heeft geen tijd om dat op een aansprekende manier voor leken toegankelijk te schrijven, dus die maakt het alweer een stukje compacter en korter en maakt het wat aantrekkelijker, door met name de vraagtekens die er zouden kunnen zijn, zouden kunnen zijn, om die verder te vergroten. Ehm, nou en dan gaat het escaleren, want, nouja, een journalist benadrukt dus in feite ook, in de meeste gevallen, om verzekerd te zijn van aandacht van zijn stuk, juist de wat negatievere aspecten, die worden het snelst benadrukt. En dat is jammer, want dan ontstaat er onrust. [...]

20) **I:** Hoe is de discussie rondom de invoering van de vaccinatie tot stand gekomen volgens u?

[...]

**HeCo:** Toen [de Minister het besluit over de invoering van het vaccin genomen had] zijn daar twee dingen gebeurd. Allereerst was er een groep epidemiologen die een artikel hebben geschreven in het Nederlands Tijdschrift voor Geneeskunde, waarin zij niet zo zeer het effect van het vaccin in twijfel hebben getrokken, als wel de vraag of dit het juiste moment was om dit al te gaan introduceren. Dat is door de media heel erg opgepakt als, kijk eens die wetenschappers zijn het allemaal helemaal niet met elkaar eens.

21) **I:** Ja, en de reden dat u dus twijfelt aan de correctheid van dat advies is ook dus gebaseerd op wetenschappelijke onderzoeken, of het gebrek aan.

**NVKP:** Ja, en de twijfel aan het advies van de Gezondheidsraad, vind ik, is buitengewoon goed verwoord, door die vier epidemiologen in dat Nederlands Tijdschrift voor de Geneeskunde. [...] Vooral Coutinho [van het RIVM] die heeft geroepen van "Ja, het is toch schandalig, dat in dit stadium wetenschappers, zo tegen het overheidsbeslissing ingaan, en dit soort discussies zouden toch niet in de publiciteit moeten plaatsvinden", nou noem maar op, al dat soort nonsens. Want dat heeft natuurlijk tot een enorme schade geleid hè. Dus, kijk, als een NVKP iets roept, dan is dat tot daaraan toe. Maar als dus vier wetenschappers, die dus tot hun kennis en kunde én kanker én de interpretatie van getalletjes mogen rekenen, als die tot de conclusie komen dat op vijf van de zeven punten, de Gezondheidsraad een verkeerde conclusie heeft genomen, ja dan gaan mensen dus denken van nou, misschien is het toch wel niet helemaal zoals het voorstelt.

22) **I:** U noemde al even Minister Klink. Heeft u op andere manier contact gehad met de overheid?

**DiMo:** RIVM. Roel Coutinho. [...] Wij zijn uitgenodigd geweest, in de zomer van 2010, naar aanleiding van die HPV-campagne. De vraag was eigenlijk, hoe kan dat het toch zo zijn dat een moeder de boel op de kop kan krijgen? Dat was de werkelijke vraag.

**I:** Ja, dus u, dus u had het gevoel dat ze met u spraken om... hun eigen campagne te kunnen verbeteren zeg maar.

**DiMo:** En niet alleen met mij, maar met ook, ehm, anderen, die tegen zijn en die voorlichting geven, dus we waren daar met meerderen. En ja, het was inderdaad om te kijken, hoe kunnen we de boel verbeteren. Want, waar de overheid nooit op gerekend had, was dat een moeder simpele gedachten kon krijgen, dat het HPV-vaccin wel eens niet zo veilig zou kunnen zijn. En dat ze gewoon via het internet de hele boel op zijn kop kon zetten. {lachend} Dat was even een misrekening.

23) **I:** Ja, u zegt al, het [de discussie] werd groter en groter. Kunt u aangeven waarom dat groter en

groter werd?

**NVKP:** Nou, omdat er met name personen zoals Anneke Bleeker [van de veronruste moeders website] kwamen. Er was dus in eerste instantie Gardasil op de markt gekomen [...] en al vanaf het allereerste begin af aan, werd het duidelijk dat dat vaccin bij sommige meiden hele nare, vervelende bijwerkingen hadden. Er werden filmpjes voor gemaakt, van huilende ouders die daardoor hun dochter hadden verloren, of een dochter die nu ernstig gehandicapt was geraakt. En dat werd allemaal dus gebonden aan dat Gardasil en dat werd bijvoorbeeld gebruikt door zo'n Anneke Bleeker op haar website, maar ook door anderen werd dat soort informatie naar buiten gebracht en dat is wat er uiteindelijk door het RIVM werd aangeduid als indianenverhalen. Die kwamen dus niet van de NVKP, maar die zijn, doordat wij dus met dat dossier zijn gekomen, bekend geworden. Ja toen zagen mensen dat er ook dus negatieve kanten aan zaten en die zijn er toen zelf mee aan de haal gegaan.

24) **I:** Kunt u omschrijven hoe de discussie rondom de HPV-vaccinatie volgens u tot stand is gekomen

**RIVM:** Tot stand is gekomen... Hmmm. Dat vind ik moeilijk te zeggen, [...] maar ik denk toch dat de Vereniging Kritisch Prikken en mevrouw Anneke Bleeker [van de veronruste moeders website], dat dat toch de vertrekpunten zijn geweest van de onrust die is ontstaan.

25) **I:** Dus eerst kwam het [advies] van de Gezondheidsraad, uw artikel was om het te nuanceren, maar de media die trok dat weer in het extreme.

**CrRe:** Vertaalt het van helemaal niet doen, ja.

**I:** Ja, dus, welke rol heeft de media dan gespeeld volgens u?

**CrRe:** Ja, een hele grote rol, ja, maar van alle kanten. Natuurlijk eerst heb je de media voor de reclameboodschappen van het product. Maarja, de media, het is gewoon precies wat ik net zei. De media maakt er gewoon een heel erg prikkelende discussie van. En die haalt er ook het liefst nog emotionele verhalen bij enzo.

26) **RIVM:** En nog één ding, in deze context, niet te vergeten, de uitzending van Zembla, in oktober. Dat is waarschijnlijk nog, nog dus eerder dan de dingen die ik nu besprak. Ik denk dat dat, zeg maar voor de publicatie van [de kritische onderzoekers] [...] Dus in de tijd, jij vroeg, waar begon het allemaal mee, hè. Nouja, dat is natuurlijk... Ik weet niet of je die gezien hebt? Dat is natuurlijk ook een hele tendentieuze, kritische uitzending.

27) **I:** En welke rol hebben dan, u noemde het als eerste, daar hebben we het verder niet over gehad, een NVKP en Anneke Bleeker, welke rol hebben zij gespeeld?

**RIVM:** Nouja, die zijn, op allerlei manieren hebben zij hun verhaal gedaan. Anneke Bleeker op televisie, ik geloof dat ik toen werd geïnterviewd voor [...] NOVA [TV-programma over achtergronden bij het nieuws], daar was zij niet bij, maar dan werden er wel filmpjes tussendoor geplakt. [...] En dan kwamen er berichten uit Amerika, van meisjes die levenslang gehandicapt waren geworden door de vaccinatie, ja. [...] Als jij toch morgen je dochter zou moeten laten vaccineren en daar komt een meisje die levenslang gehandicapt is geraakt en je bent niet inhoudelijk deskundig natuurlijk, dan zou je toch ook tien keer nadenken of je je dochter wel gaat laten vaccineren? Ik, ja... Maarja, goed, ze deputeren dat en ik kan proberen dan op dat moment het te weerleggen, maar tegen zo'n ernstig beeld, dan kan je wel leuk de Rijksvaccinatie Programma manager twee minuutjes iets

laten zeggen, maar of dat dan weg is die angst? Dat vraag ik me af.

28) **I:** Ja, welke rol hebben de media volgens u gespeeld in de totstand koming van de onrust, in Nederland?

**Pha2:** Nouja, kijk media, als je het hebt over de social media, daar is het ontstaan, dat is de bron geweest van de onrust. En de social media zijn dan YouTube, Facebook en Hyves. Of Facebook toen eigenlijk nog niet zo, het was vooral Hyves en YouTube, dat dat op dat moment ingezet werd. In die tijdsgeest was Hyves nog groot en de traditionele media, zeg maar, gewoon de prints en radio, TV ook wel af en toe, die hebben het debat flink beïnvloed, daar is echt de onrust gecreëerd ook, door een aantal journalisten die echt op, ja, die vonden dit wel interessant. Die hebben een podium gegeven aan criticasters en dat is zeker niet de schuld van de media trouwens, want ik vind media doen gewoon wat ze moeten doen, dat is namelijk kritisch zijn en onderzoeken. [...]

29) **Pha2:** [...] Maar het is een discussie die de overheid volstrekt, en dat vind ik echt de verantwoordelijkheid van de overheid hoor, dat ze die volstrekt uit de hand hebben laten lopen: niet reageren, de verkeerde dingen doen, hè, artsen een rechtzaak aan de broek geven. Ja, dat is niet hoe het werkt denk ik in deze wereld. [...] Ja, en wat heb je, kijk, dan heb je nog wel de traditionelere media, de websites van de overheid, ja, waar wel informatie op stond, die op zich ook wel klopte, maar dan nog zover weggestopt dat ik ook nog moest zoeken als consument, dus, ja, dat is geen antwoord geweest eigenlijk.

30) **I:** En welke rol hebben media gespeeld? In de discussie?

**ScJo:** [...] Spelen media daarin echt zo'n rol? Ze zijn toch meer platform voor meningen. [...]

**I:** Nou, u kunt bijvoorbeeld denken aan een uitzending van NOVA, uitzending van Zembla, van Radar, ik weet niet of u die gezien heeft?

**ScJo:** Ja, jaja, maargoed, dat is toch voor een groot deel reactief. Er zijn dan onderzoekers die vinden iets, en dan maken ze, dan maakt Zembla daar een uitzending over. [...] Kijk, wat de media doen weet ik wel, maar wat hun rol is in de discussie is natuurlijk een stuk onduidelijker, of mensen daar wat van aantrekken of niet.

**I:** Ja, nou, Roel Coutinho heeft wel genoemd dat media bepaalde partijen teveel aandacht zouden geven en daardoor mensen een stem zouden geven, die, ja... Hij heeft ooit het woord indianen verhalen ook gebruikt.

**ScJo:** Jaaa, maar dat is natuurlijk een beetje oneerlijk. Zijn taak is er voor zorgen dat die indianenverhalen snel de kop in worden gedrukt en op de een of andere manier niet kunnen ontstaan. Als hij een slechte campagne voert en indianenverhalen kunnen doorgaan, ja, dan heeft hij iets niet goed gedaan.

31) **I:** Had de discussie hélemaal voorkomen kunnen worden denkt u?

**Pha2:** Ja, kijk discussie kun je hebben. Maar je had gewoon, als je vanaf het eerste begin, ingegrepen had en meegedaan had met de discussie als overheid, dan had je een heleboel ellende kunnen voorkomen, daar ben ik van overtuigd. Als je duidelijk had gezegd wat je vindt en positie had gekozen en ja, dat is zeker het geval.

32) **I:** Welke rol heeft de overheid gespeeld in de totstandkoming van de discussie? U zei al dat ze de scherven, de scherven op moesten rapen. Waarom moesten ze de scherven oprapen?

**ScJo:** Nouja, de Minister had besloten dat het ingevoerd moest worden, op advies van de Gezondheidsraad. [...] Terwijl er dus nog een maatschappelijke discussie woedde. En dat maakt het lastig om iets te implementeren en die opdracht kreeg het RIVM, gewoon omdat zij het Rijksvaccinatieprogramma doen, maar dit was natuurlijk wel wat anders. En ze waren eigenlijk volstrekt niet geëquipeerd volgens mij, ze dachten zelf van wel denk ik, maar om goed zo'n programma op te zetten om mensen te overtuigen dat het nuttig was, hè, om de Vereniging Kritisch Prikken weerwerk te bieden, ook om onderzoekers die zich in de discussie mengde, zich van het lijf te houden. Ze lieten dat voor mijn gevoel, maarja dat is mijn observatie van ver weg, volstrekt uit hun handen vallen. Ze hadden volstrekt onderschat wat ze te doen kregen van de Minister.

33) **I:** En welke rol heeft volgens u de overheid in de discussie? In hoe zij het vaccin uiteindelijk geïntroduceerd hebben?

**HeCo:** Nou ik denk dat het RIVM met name geen rekening heeft gehouden met de social media. Dat hebben ze ook toegegeven, dat ze dat misschien niet handig hebben gedaan, dat ze te veel zijn gaan varen op de gedachte dat je, nou, dat iedereen wel voor zoete koek aanneemt als je iets wordt aangeboden.

34) **I:** Ja. Dus als je ergens een pijnpunt, als ik het zo mag noemen, aan zou moeten wijzen, is het de eerste communicatie naar de burgers toe?

**VWS1:** Achteraf. Dat is achteraf, want ik denk dat er best wel wat dingen samenliepen, [...] als we dat achteraf gezegd, allemaal op een rijtje hadden, zo expliciet ons hadden gerealiseerd en helder hadden, dan hadden we misschien toen al besloten om in communicatie een andere teneur te kiezen. Dat hebben we niet gedaan.

**VWS2:** Ja, ik vind... Op dat punt denk ik dat ik er iets anders tegenaan kijk, maar ik weet het ook niet, ik bedoel, het kan zijn dat het bij elkaar kwam, het kan ook zijn dat we het geïnitieerd hebben, om het bij elkaar te laten komen, door middel van dit vaccin. En ik heb een beetje het gevoel dat het een, maar goed, ik heb ook natuurkunde gestudeerd ooit, dat het een soort condensatiekern is geweest, voor dit soort meningen, die een vrij simpel aangrijpingspunt hadden om hun meningen er eventjes goed overheen te leggen.

**VWS1:** Ja ik kan me voorstellen dat je het zo ziet..

**VWS2:** Maar het kan van twee kanten, ik bedoel, ik weet ook niet precies wat waar is. Ik weet wel dat waar is, dat wij het in onze communicatie en in de invoering behandeld hebben als een klassiek vaccin. En ik denk dat dat, met de kennis van nu, naïef is geweest. Want het was geen klassiek vaccin, niet vanwege de eigenschappen van het vaccin, niet vanwege de eigenschappen van de kinderen en niet vanwege de eigenschappen van de doelgroep.

35) **I:** U zei net, de reactie van het RIVM verdiende niet de schoonheidsprijs, u zou u die reactie omschrijven dan?

**Gyne:** Nou, zij zijn niet bij zichzelf gebleven, bij hun eigen kracht gebleven, namelijk het neerzetten en uitleggen hoe goed het RIVM nu al, toentertijd en ook nu nog steeds, omgaat met het Rijksvaccinatieprogramma, met de vaccins die daar onderdeel van zijn. En ze hebben zich niet beperkt tot de inhoud, maar ze hebben ook gesproken over vorm en dat is niet verstandig. En met betrekking tot de discussie over de inhoud hadden ze veel beter moeten nadenken over de populatie waar het om gaat, jonge meisjes in de leeftijd van twaalf en de

inhaalvaccinatiecampagne, dertien tot zestien, dat je, als je die ook een stem geeft in wel of niet komen [...] dat je hen op een hele andere manier moet benaderen. Dat die communicatie gewoon op een hele andere wijze loopt. En dat kan elke ouder van kinderen in die leeftijdscategorie je vertellen. Zoals ik. En dat is niet goed gedaan en niet goed gegaan.

36) **I:** Heeft de farmaceutische industrie nog op andere punten [behalve het subsidiëren van onderzoek] een rol gespeeld in de, in de hele discussie, in de hele invoering?

**CrRe:** Ja, absoluut, dat eh, ja ik denk dat zij ook wel de grote drijfveer voor de discussie zijn geweest, want ja, er zijn ook natuurlijk twee grote invallen geweest bij de, bij allebei de bedrijven. Omdat ze dachten dat ze op een illegale manier reclame maakten, want in Nederland mag je natuurlijk geen reclame maken voor medicijnen. Maar wat er wel gedaan werd, er werd reclame gemaakt voor een ziekte. Baarmoederhalskanker was ineens, overal dook het op. Maarja, het is helemaal niet zo'n groot ding in Nederland, baarmoederhalskanker is echt hardstikke goed onder controle door het bevolkingsonderzoek. En ineens was dat overal, Angela Groothuizen natuurlijk met haar spotje van bescherm je dochter en natuurlijk dat prikkelt vrouwen wel, iedereen die wil zijn kinderen beschermen dus dat, ja.

37) **I:** Welke rol heeft de farmaceutische industrie gespeeld?

**HeCo:** Nou, die zijn behoorlijk op de reclametoer gegaan. En dat hebben ze niet handig aangepakt. Omdat daardoor denk ik, ik denk dat dat ook wel een rol gespeeld, dat mensen daardoor de indruk kregen dat er veel te veel commerciële belangen mee gemoeid waren. Zij hebben bijvoorbeeld georganiseerd dat er voorlichtingsavonden werden gegeven in ziekenhuizen. Nouja, kijk, als er een nieuw middel voor hoge bloeddruk op de markt komt, dan gaat er toch nooit iemand naar een voorlichtingsavond in een ziekenhuis om daar wat over te horen van de internist. En dat hebben ze dus nu wel gedaan en dat, dat vond ik niet slim en ik heb ook altijd geweigerd om daaraan mee te werken.

38) **I:** U zei ook dat zij [de industrie] pushte om het er doorheen te krijgen. Welke rol hebben ze daarin gespeeld?

**ScJo:** Nouja, goed, hun taak, hun taak is natuurlijk om het vaccin te verkopen, wat ze voor veel geld ontwikkeld hebben. Dus zij willen graag dat overheden hun vaccin, omarmen en in het vaccinatieprogramma opnemen. En, ja god, dat doen ze met alle middelen die er zijn. Meestal legaal, maar soms ook een beetje illegaal.

**I:** Wat vindt u zelf van de manier waarop dat gegaan is?

**ScJo:** Nouja, ik vind het dus ongelooflijk stom om nog voordat er een besluit is geweest van de regering, om dan al op het schuldgevoel van moeders te gaan spelen. Dat moet je niet doen als je geen goede naam hebt. Ik bedoel, Albert Heijn zou het kunnen, maar farmaceutische industrie moet zich naar mijn gevoel in, in dit soort dingen gedeisd houden, maarja, ik ben niet van de PR-adviezen, dus ik weet het niet. Maar ik heb idee dat ze, dat daarmee al heel veel verpest is voor het RIVM later. Want die kwamen met dezelfde boodschap, maar dan officieel, en ja, dan, dan is het natuurlijk een stuk lastiger.

39) **I:** Hoe is de discussie over de invoering van de HPV-vaccinatie volgens u tot stand gekomen?

**Gyne:** Dat is wel héél erg algemeen. Hoe is de discussie tot stand gekomen? Met andere woorden: wie heeft hem geïnitieerd? Zou je daaruit kunnen destilleren als eerste vraag. Dan denk ik dat je moet stellen dat de driving force om het een onderwerp te laten zijn in Nederland, is de farmaceutische industrie geweest.

**I:** En hoe wordt het dan een discussie?

**Gyne:** Zij hebben het een onderwerp gemaakt, niet alleen bij de specialisten die direct betrokken zijn, bij mensen zoals ik. Maar zij hebben [...] om voor hun moverende redenen, anderen van informatie voorzien. En dan gaat het breed, dan gaat het van mensen in de politiek, Tweede Kamer-leden, overheidsinstanties, maar ook de publieke media door voortdurend press-releases uit te laten gaan, hebben ze bewust ervoor gekozen, denk ik, daar ben ik niet bij geweest, om dit een discussie te maken in Nederland.

**I:** Heeft u een idee waarom zij er baat bij hebben als het een discussie wordt?

**Gyne:** Als ik het dus vrij interpreteer en dan denk ik dat ze gezocht hebben naar een manier om Nederland warm te maken voor dit vaccin. Ze hadden klaarblijkelijk het idee dat dit verstandig was, om dit zo te doen.

40) **I:** En ehm, kun je daar als farmaceutisch bedrijf nog een rol spelen, in die discussie?

**Pha2:** Nee, wij hebben, als farmaceutisch bedrijf mag je niet communiceren over jouw producten aan het algemeen publiek, dus we hebben het echt met de handen op de rug moeten aanzien.

**I:** Ok. Maar als ik goed geïnformeerd ben, hebben de farmaceutische bedrijven wel aandacht gevraagd voor de ziekte, door middel van, bijvoorbeeld Sanofi, ook een spotje. Wat is het doel daarvan, om die aandacht te vragen?

**Pha2:** We hebben marktonderzoek gedaan, natuurlijk ver voordat dat vaccin geïntroduceerd werd van, maar weten mensen eigenlijk van die ziekte, want dit is best een ingewikkeld verhaal om uit te leggen. [...] Nou, daar bleek dat mensen geen flauw benul hadden van hoe vaak het voorkomt, hoe je het kunt krijgen en wat je er aan kunt doen om het te voorkomen. Dus wij hebben gezegd, en dat mag als farmaceutische bedrijven ook van, we gaan mensen proberen duidelijk te maken wat eigenlijk die ziekte is. [...] Er is toen een vrij grote campagne opgestart om mensen bewust te maken van wat is het, met een website en een beroemde Nederlander, en alles erop en eraan, om in ieder geval voorlichting te geven over waar gaat het nou eigenlijk over als je het over baarmoederhalskanker hebt.

41) **I:** Want wat zou er gebeuren als u, als u, als dat bewustzijn er niet zou zijn?

**Pha2:** Nouja, dan krijg je denk ik mensen veel moeilijker gemotiveerd om een prik te halen, want dan snapt niemand waarom dat nou moet eigenlijk. [...] Wat ik zeg, een briefje krijgen van de overheid, van je moet een prik halen, is gewoon niet meer voldoende om mensen te motiveren. Je moet ze ook uitleggen waarom dat dan nodig is en dan, daar hoort ook bij dat je uitlegt wat is het eigenlijk voor ziekte, en hoe ontstaat ie en, nouja, alles er omheen. [...]

**I:** Ja. Heeft het denkt u het gewenste effect gehad die campagne?

**Pha2:** Dat is moeilijk te zeggen. Ik denk... Ja, nou, hij heeft een, even kijken, als het gaat over bewustwording bij mensen zeker wel. Want we hebben dat gemeten ook, van heeft dat marktonderzoek nou tot aantoonbare verhoging van die kennis geleid, en dat was zeker zo.

42) **I:** Er zijn ook journalisten geweest en die zijn gaan zoeken naar, die hebben ingespeeld op de al dan niet afhankelijkheid, onafhankelijkheid, van bijvoorbeeld de Gezondheidsraad of van andere



mensen bij de overheid. Wat vindt u daarvan?

**Pha1:** Nou, ik denk dat dat heel gezond is en dat het heel belangrijk is, dat iedereen er vanuit kan gaan en, want zo moet het zijn, dat advies, advisering en trouwens ook het nemen van beslissingen op het Ministerie, dat dat in onafhankelijkheid plaatsvindt. [...] bij onafhankelijkheid wordt altijd meteen gedacht: industrie. Maar ik denk dat je die onafhankelijk veel breder zou moeten trekken en dat het zou beter benoemd moeten worden. Want bijvoorbeeld, waar jouw vraag nu ook, waar die niet over gaat, maar of het wel heel interessant is om te kijken of onderzoekers onafhankelijk zijn vanuit hun eigen belang. Niet zo zeer vanuit een mogelijke geldstroom vanuit de industrie, maar onderzoekers, ja, die moeten natuurlijk ook projecten binnen halen, van NWO, van andere subsidiërende organen die er zijn. [...]

43) **I:** Ja, en probeert u dan nog te helpen om die schijn [van belangenverstrengeling] weg te nemen? Probeer u nog te zorgen dat die schijn er niet is. Houdt u zich daarmee bezig?

**Pha1:** Nouja, kijk, daar moet je altijd goed over nadenken. Dus wat ik al eerder in het gesprek zei, als wij wetenschappelijk onderzoek laten plaatsvinden, [...] daar kies je dan als fabrikant voor, om dat te financieren, er zijn dan mensen die al zeggen van "oh, wacht even, dat is onderzoek gefinancierd, die meneer, die expert, doet onderzoek gefinancierd door een fabrikant die een belang heeft". Nou, zo kun je het neerzetten, je kan ook zeggen, de fabrikant heeft behoefte aan onafhankelijke experts, die met de expertise die ze hebben verkregen, proberen de bewijsvoering voor de werkzaamheid van hun product zo goed mogelijk, zeg maar, te onderbouwen. Dat is natuurlijk ons perspectief. [...]

44) **Pha1:** [...] Het feit dat wij met onafhankelijke experts werken, ze volledig transparant en op contractbasis daarvoor een tegenprestatie bieden, nouja, die, hetzelfde onderzoek als hij in zo'n onderzoeksvoorstel schrijft, ook op precies dezelfde manier neer zou leggen bij een subsidiërend overheidsorgaan, ja, dat zijn de principes waar we in Nederland langs werken. En daar kun je heel kritisch over zijn, je kan er vanalles in zien, maar de feiten zijn de feiten.

45) **DiMo:** Het [de bespreking van het boek "Chemo? Of kan ik zelf kiezen?"] mocht niet in de krant. Dat boek, dat is vrij onthullend op een heleboel vlakken [onder andere chemotherapie] en dat mag niet.

**I:** Van wie niet dan?

**DiMo:** Oncologie [-afdeling van het ziekenhuis Alkmaar]. Kanker is een ziekte zeggen ze. Maar kanker is een industrie. En het Koningin Wilhelmina Fonds, dat mag helemaal niet opgeheven worden, want dat kost topsalarissen. Er werken meer mensen in de kankerindustrie, dan dat er mensen zijn die kanker hebben, bij wijze van spreken.

46) **I:** Welke rol hebben media gespeeld, in de discussie, volgens u?

**DiMo:** Nouja, de media is ook niet vrij. Er is geen persvrijheid in dit land. En dat is gewoon te merken op alle fronten, hoe iets wel of niet geplaatst wordt. En hoe je, eh, gemanipuleerd wordt, hoe ze over je schrijven, dingen die je niet gezegd hebt die ze rustig in de krant zeggen dat jij ze hebt gezegd. Nee, dat is ook één groot verhaal. En ook die worden weer door de overheid in de gaten gehouden.

47) **I:** Waar kwam die eerste informatie vandaan, waar de discussie over kwam?

**CrRe:** Uit literatuur. In ieder geval, waar wij de de discussie [over voerden], de discussie werd op gegeven moment natuurlijk veel groter getrokken. Maar waar we voor het Gezondheidsraad advies en onder wetenschappers werd het natuurlijk eerst gewoon gebaseerd op wetenschappelijke feiten.

48) **I:** Welke rol heeft wetenschappelijke informatie volgens u gespeeld in de discussie?  
**Pha2:** Ja, in de maatschappelijke discussie weinig. Te weinig. In de echte discussie zeg maar, onder diegene ja, die bepalen, onder de Gezondheidsraad en het RIVM, heel veel. Ik denk dat dat, daar is echt op basis van pure feiten gekeken. [...]

49) **NVKP:** [...] Waar wij als NVKP voor staan is dus dat de uitlatingen die wij doen, die moeten allemaal een wetenschappelijke fundatie hebben. Hè die moeten dus, dat moet dus niet iets zijn, een ouder roept "mijn kind is overleden aan een vaccin", dat wij zeggen van, hup, dat vaccin moet je verbieden.

50) **I:** Welke rol heeft wetenschappelijke informatie gespeeld in de discussie? Hoe gebruikt u het zelf?  
**DiMo:** Ja, welke wetenschappelijke informatie? Vanuit?  
**I:** Eehm, ja, wetenschappelijke informatie is in deze zin gepubliceerde artikelen.  
**DiMo:** Kijk, objectieve wetenschappelijke informatie, daar hechten wij waarde aan. Maar zogenaamde wetenschappelijke informatie vanuit meneer Osterhaus [een publieke expert op het gebied van virologie en influenza] en de zijnen, daar hechten wij geen waarde aan, want daar zitten de belangen achter.

51) **I:** U heeft dus te maken gehad met, wat genoemd wordt, experts van de Gezondheidsraad. Heeft u ook nog met andere onderzoekers te maken gehad?  
**DiMo:** Nouja, wat ik al zei, wij krijgen rapporten, wereldwijd, van artsen, van mensen die objectief kijken, maar die ook weer belachelijk gemaakt worden door diezelfde Gezondheidsraad, RIVM en Ministergroep.  
**I:** En objectief betekent voor u?  
**DiMo:** Objectief is dat je geen belangen hebt in de farmacie. Geen belangen hebt in het wel of niet spuiten en slikken. Ik bedoel ik heb geen aandelen, ik word niet betaald.

52) **I:** Zijn er ook objectieve wetenschappers die wel zeggen dat vaccineren goed is?  
**DiMo:** Nee, die zijn er niet.

53) **VWS2:** Kijk en altijd geven we informatie over vaccins in dit geval. Specifiek op de RIVM website, passieve informatie, waarvan wij vinden dat het objectieve informatie is. Kijk als je per definitie vindt dat het RIVM cq. de overheid niet-objectieve informatie geeft, dan is daar niks tegen te doen. Want, ik bedoel, dat is een mening, dat is een beeldvorming, die je moeilijk van de ander kant- Ik bedoel, wetenschappelijk gesproken is datgene wat het RIVM geeft, objectieve informatie.

54) **I:** Ja, want wat zij zelf bijvoorbeeld zeggen, de NVKP, is dat ze zich wel baseren op wetenschap en met referenties komen en dergelijke. Maar u vindt dat niet, dat ze zich baseren op wetenschap?

**Gyne:** Kijk als je je op wetenschap baseert, betekent het dat je 1. je dan moet baseren op goede wetenschappelijke artikelen en 2. dat je ook de juiste dingen uit het artikel haalt en niet alleen een tussenzin uit zijn verband haalt en die vervolgens quote. Nou, u weet waarschijnlijk net zo goed als ik, dat als je op de site van Kritisch Prikken gaat kijken, dat je mijn naam kunt vinden onder een tegenstander van dit vaccin. Nou, dat is heel interessant. Want ik ben veel, maar zeker geen tegenstander.

**I:** Waarom denkt u dat zij dan toch zeggen dat zij zich op wetenschap baseren, waarom zouden ze dat doen?

**Gyne:** Omdat dat heel goed bekt op die manier. Zij weten ook wel dat als je overtuigend wil overkomen, dan moet je zeggen dat je je op wetenschappelijke artikelen baseert, de mening die je hebt.

55) **I:** Ok, dus u probeert daarmee [met het gebruik van wetenschap] ook geloofwaardig over te komen.

**NVKP:** Wij proberen geloofwaardig over te komen, doordat wij bijvoorbeeld, als je naar mijn HPV-dossier kijkt, daar staan tien-tallen bronvermeldingen bij. Hè, er is dus geen bewering die wordt gedaan, zonder dat daar een wetenschappelijk onderzoek, een bron aan ten grondslag ligt.

56) **I:** Hoe zou u wetenschappelijk gezag definiëren?

**ScJo:** Gezag is dat mensen naar je luisteren, ze hoeven het niet met je eens te zijn, maar ze luisteren wel naar je.

57) **I:** Wat verstaat u onder het gezag van wetenschap?

**HeCo:** Dat mensen aannemen dat als deskundigen ergens over nadenken en een studie op een juiste manier hebben gedaan, dat op basis daarvan keuzes worden gemaakt over hoe wij dingen doen in de zorg.

**I:** Ok, dus, het advies van deskundigen aannemen.

**HeCo:** Ja, dat mensen het advies van deskundigen aannemen.

58) **I:** Als u dan gezag, het woord gezag moet definiëren, waaruit blijkt gezag?

**NVKP:** Gezag, is dus als iemand iets zegt, dat het ook gebeurt, of dat het waar is, dat is gezag.

59) **I:** Wat tegenwoordig populair is om te zeggen is dat het gezag van wetenschap in het gedrang is, dat hoor je in de media. Wat verstaat u onder het gezag van wetenschap? Wat wordt daarmee bedoeld als mensen dat zeggen?

**Vac2:** Nou ik denk dat ermee bedoeld wordt, vertrouw jij als, gewoon als Nederlander, als consument, wat een wetenschapper zegt [...] ik denk over het algemeen, als jij zegt: "Ik ben een expert, ik ben een arts en ik heb patiënten onder behandeling en ik vind dit het beste", dat dat echt wel een hele betrouwbare afzender is.

60) **I:** Wat verstaat u dan onder autoriteit? Wanneer heeft iemand autoriteit?

**RIVM:** Ja, ik denk dat autoriteit te maken heeft, ten eerste met expertise, kennis en kunde. En een andere element is misschien ook, geloofwaardig, overtuigingskracht, dat soort elementen zitten er denk ik in. [...]

61) **I:** En hoe zou u het gezag definiëren? Wat is gezag?

**VWS1:** Nou, dat is zowel de overheid die besluit wat goed voor je is, of de overheid waar je in vertrouwt, dat zij handelt in het belang van, in elk geval de gemeenschap. Maar ook de arts die inderdaad zegt wat goed voor je is.

62) **I:** Maar daar [de wetenschappelijke methode] ontleent dan wetenschap zijn gezag aan? Dat het de manier is om feiten te-

**CrRe:** Ja, dat is de, ja, zo gauw je... Ik denk niet dat bijvoorbeeld, dat als een bedrijf probeert feiten boven water te krijgen, een bedrijf dat zelf een product maakt en dat zelf wil laten zien hoe goed het product is... Ja, dan ben je natuurlijk helemaal niet onafhankelijk. Dus is denk wel dat het de enige tool is...

**I:** Dus onafhankelijkheid is eigenlijk een voorwaarde voor... ?

**CrRe:** Voor dat ja, voor dat gezag, denk het wel, ja.

63) **I:** Er wordt de laatste maanden meer gezegd dat het gezag van wetenschap in het gedrang zou zijn. Wat verstaat u onder wetenschappelijk gezag?

**NVKP:** Voor mij is dat niet een term die ik zelf zou hanteren, wetenschappelijk gezag. Voor mij is het zo dat, een wetenschapper moet zoveel mogelijk onafhankelijk zijn, moet integer zijn, moet ethisch verantwoord handelen.

64) **I:** Ja, maar wetenschap kan wel gebruikt worden, wetenschappelijk onderzoek, om gezag te creëren? Zeg ik het goed? Als ik het goed begrijp, probeert u met uw organisatie door middel van u te baseren op wetenschappelijk onderzoek, toch geloofwaardig over te komen.

**NVKP:** Nou, wat wij proberen, wat wij eigenlijk laten zien, is dat dat gezag waar jij het over hebt, dat bolwerk, dat daar dus barsten in zitten en dat er dus heel makkelijk ander wetenschappelijk onderzoek, naar voren geschoven kan worden, waardoor dus die mensen die dus roepen, van jongens, wij zijn gezaghebbend en als wij iets zeggen dan is het zo, dat dat gezag, niet alom wetend is, en [niet] onkreukbaar is en [niet] dat je daar niet aan hoeft te twijfelen.

65) **I:** Ik heb nog een vraag over het gezag van wetenschap in de samenleving. Wetenschap heeft een zeker soort gezag, experts hebben een soort gezag-

**DiMo:** Wat zijn experts?

**I:** Ja, nou, precies, dat is mijn vraag dus.

**DiMo:** Weet je, een expert, die zijn wetenschappelijke rapporten door een ghostwriter laat schrijven, die is voor mij een grote minkukel. En, de grote, het overgrote gedeelte van onze bevolking, loopt als makke schapen overal achteraan. En dat is ook wel lekker gemakkelijk, dan hoeft je zelf niet na te denken.

66) **I:** Bent u het met me eens als ik zeg, er is gezag, of dat dan wetenschap of overheid is, omdat mensen niet zelf nadenken.

**DiMo:** Ja... Dat gezag is voor mij één groot lachertje, echt.

**I:** Ja, maar het is er. Want u zegt net zelf, mensen die mensen volgen wat ze zien, dus het gezag is er-

**DiMo:** Ja, maar dat is juist het punt, men dént, men dént dat dat goed is. Men dént dat het gezag gelijk heeft, nou het gezag heeft niet gelijk en het gezag is ook één en al manipulatie. [...] Hoezo gezag?! Ik heb er geen óntzag voor.

67) **I:** En waarom denkt u dat de opkomst dan zo laag was. Wat denkt u dat ouders er toe bewogen heeft om het niet te gaan doen?

**HeCo:** Ik denk dat het feit dat ouders de indruk kregen, goh ze zijn het niet met elkaar eens, dus het zal wel niet zo duidelijk zijn. Ja, en, een soort nieuwe beweging dat het publiek niet meer allemaal zomaar aanneemt wat de overheid, wetenschappers, deskundigen op een bepaald gebied zeggen. Dat is een soort van nieuwe beweging lijkt wel, hè?

68) **I:** Denkt u dat het iets van deze tijd is, dat dus die andere [persoonlijke] kant moet komen [in de boodschap van de overheid naar het publiek]? Dat dat voorheen niet speelde?

**VWS1:** Ik denk dat dat minder speelde. Ik denk dat met de, met al die sociale media wel het makkelijker aansteekt. En met het afgenomen vertrouwen in de overheid en het afgenomen vertrouwen in de witte jas, hè, dus er is toch wel wat meer kritiek [...]

69) **I:** U noemde al minder vertrouwen in de overheid en minder vertrouwen in de witte jas. Waar merkt u dat uit?

[...]

**VWS1:** Waar zie je dat aan? Dat vind ik een moeilijke vraag.

**VWS2:** Nou, aan het feit, een heel simpel voorbeeld, ik bedoel, ik kan me, volgens mij uit de griepperiode, herinneren dat er een uitzending van Pauw & Witteman was, waarbij de voorzitter van de NHG zat, een huisarts zelf. Die werd geconformenteerd met de claims van die mevrouw [van de verontruste moeders], die vond dat er niet gevaccineerd moest worden. En zijn, wat mij betreft gevleugelde uitspraak was: hoe zijn we in hemelsnaam in de situatie waarin het, de mening van een ex-verpleegster, op hetzelfde niveau wordt gesteld als de mening van dertig deskundigen die er vijf uur over vergaderd hebben [...].

**VWS1:** Ja, dat is het misschien ook een beetje, hè. Maar dat is ook niet "waar zie je dat aan?", maar elke mening die op internet wordt gezet krijgt evenveel gewicht, bij wijze van spreken. Maar ik heb het ook het idee, dat het vertrouwen in gezag, of de gezagsbereidheid ofzo, dat neemt af, is afgenomen, maar waar je dat aan ziet dat weet ik niet.

70) **I:** Wat verstaat u dan onder autoriteit? Wanneer heeft iemand autoriteit?

**RIVM:** Ja, ik denk dat autoriteit te maken heeft, ten eerste met expertise, kennis en kunde. En een andere element is misschien ook, geloofwaardig, overtuigingskracht, dat soort elementen zitten er denk ik

in. Maar dat geloofwaardigheid is dus tegenwoordig juist helemaal niet meer zo, dat iemand die op basis van zijn deskundigheid iets deputeert, die wordt eigenlijk een beetje met wantrouwen aangekeken. [...]

- 71) **I:** Bent u het eens met dat het gezag in het gedrang is?
- HeCo:** Ja, dat weet ik niet precies, dat, die indruk krijg je wel een beetje.
- I:** En waaruit krijgt u die indruk?
- HeCo:** Of dat nou het gezag van de wetenschap of het gezag van de overheid is? Dat weet ik niet precies. Het zou ook heel erg het gezag van de overheid kunnen zijn. Maar het wordt soms ook wel een beetje overtrokken.
- I:** Hoe bedoelt u dat?
- HeCo:** Nou, van die lekkere quotes uit de media.

- 72) **I:** Wat tegenwoordig populair is om te zeggen is dat het gezag van wetenschap in het gedrang is, dat hoor je in de media. Wat verstaat u onder het gezag van wetenschap? Wat wordt daarmee bedoeld als mensen dat zeggen?
- Vac2:** Nou ik denk dat ermee bedoeld wordt, vertrouw jij als, als, gewoon als Nederlander, als consument, wat een wetenschapper zegt. En ik werk nu toevallig bij een bureau die dat vertrouwen elk jaar onderzoekt, dus wij hebben een heel goed beeld in hoe dat zich nou ontwikkelt in de loop van de jaren. En wat je ziet is dat het vertrouwen van burgers in de overheid steeds minder wordt, dat daalt echt elk jaar weer. Maar dat het vertrouwen van burgers in echte experts, hoog is en hoog blijft ook, zelfs weer licht toeneemt. [...]

- 73) **I:** Ja. Dus als je ergens een pijnpunt, als ik het zo mag noemen, aan zou moeten wijzen [in het optreden van de overheid], is het de eerste communicatie naar de burgers toe?
- VWS1:** Achteraf. Dat is achteraf, want ik denk dat er best wel wat dingen samenliepen, [...] in [een] tijd met het steeds kritischer worden van bepaalde groepen ten aanzien van vaccineren en ook ten aanzien van de betrouwbaarheid van de overheid. Hè, je ziet dat de burger de overheid steeds minder betrouwbaar vindt [...]

- 74) **I:** Merkt u zelf iets van, dat, de afname van gezag, met de recente discussies?
- CrRe:** Nee.
- I:** Of is het juist zo, door de aandacht die het artikel gekregen dat dat juist meer een bevestiging is van dat het wel gezag heeft.
- CrRe:** Ja, want dan was het, als je googlet op dat stuk van ons, dan komt het overal zo van, dit zijn echte, dit zijn wetenschappers, experts en die zeggen ook dit of dat, weetjewel, dus ik denk juist dat je gezag gebruikt werd om, ja, om het geluid te verkopen.

- 75) **I:** Ja. Heeft u het gevoel dat wetenschappers wél autoriteit hadden in de discussie?
- Vac2:** Jaha, die hebben wel degelijk [autoriteit], anders besluit ook niet de helft van de kinderen om die prik wel te halen. Ze hebben dat wel gedaan en er zijn veel mensen naar een huisarts gestapt, naar een dokter, en veel dokters hebben gezegd: nee, doe het maar, want het is veilig en het is goed.

Dus absoluut heeft de autoriteit geholpen in deze discussie. Ja.

- 76) **I:** Bent u het eens met de uitspraak dat het gezag van wetenschap in het gedrang is?
- ScJo:** Wetenschappers hebben wel gezag, dat blijkt uit de hoeveelheid geld die erheen gaat [voor onderzoek]. Maar ook uit het feit dat wetenschappers die een ander geluid laten horen, gebruikt worden door tegenstanders.