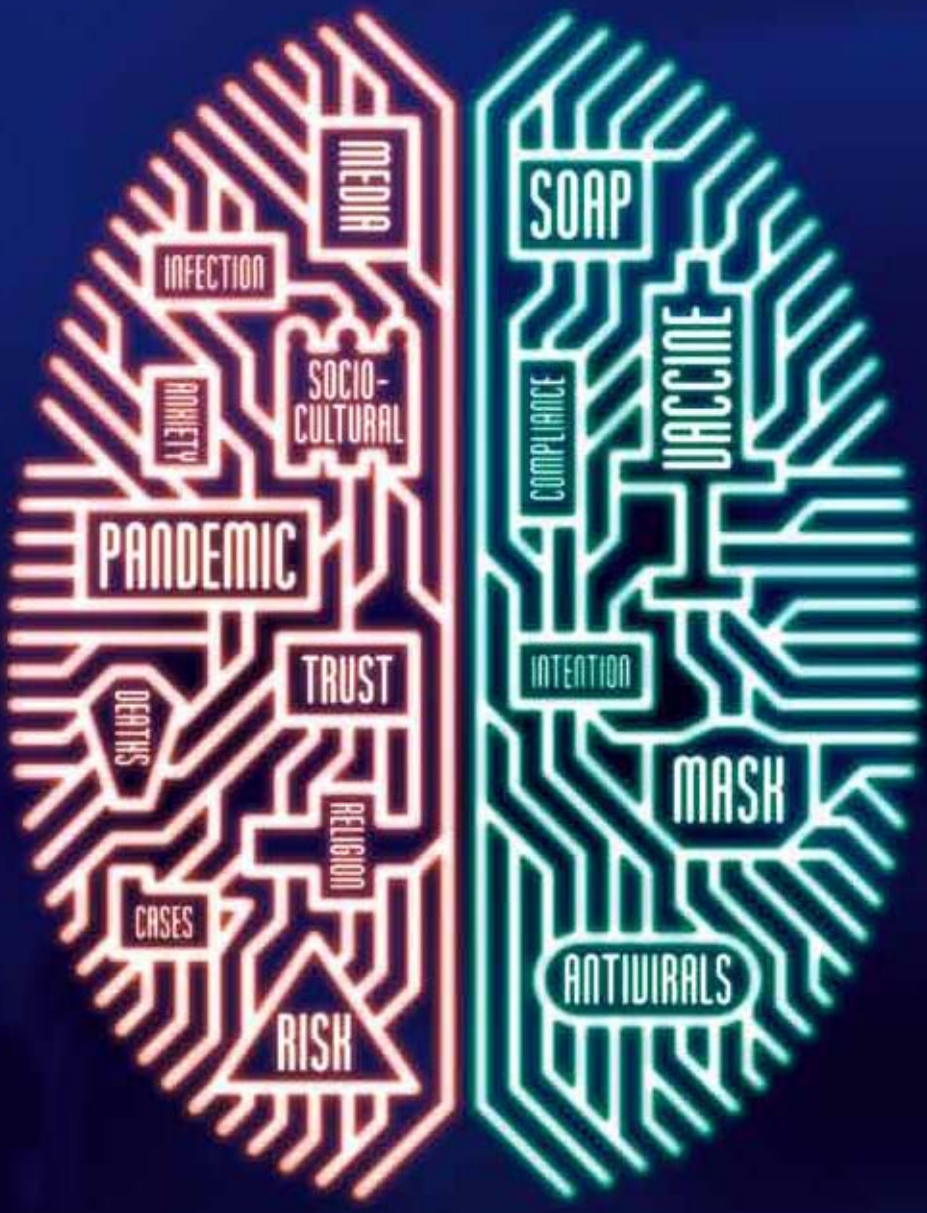
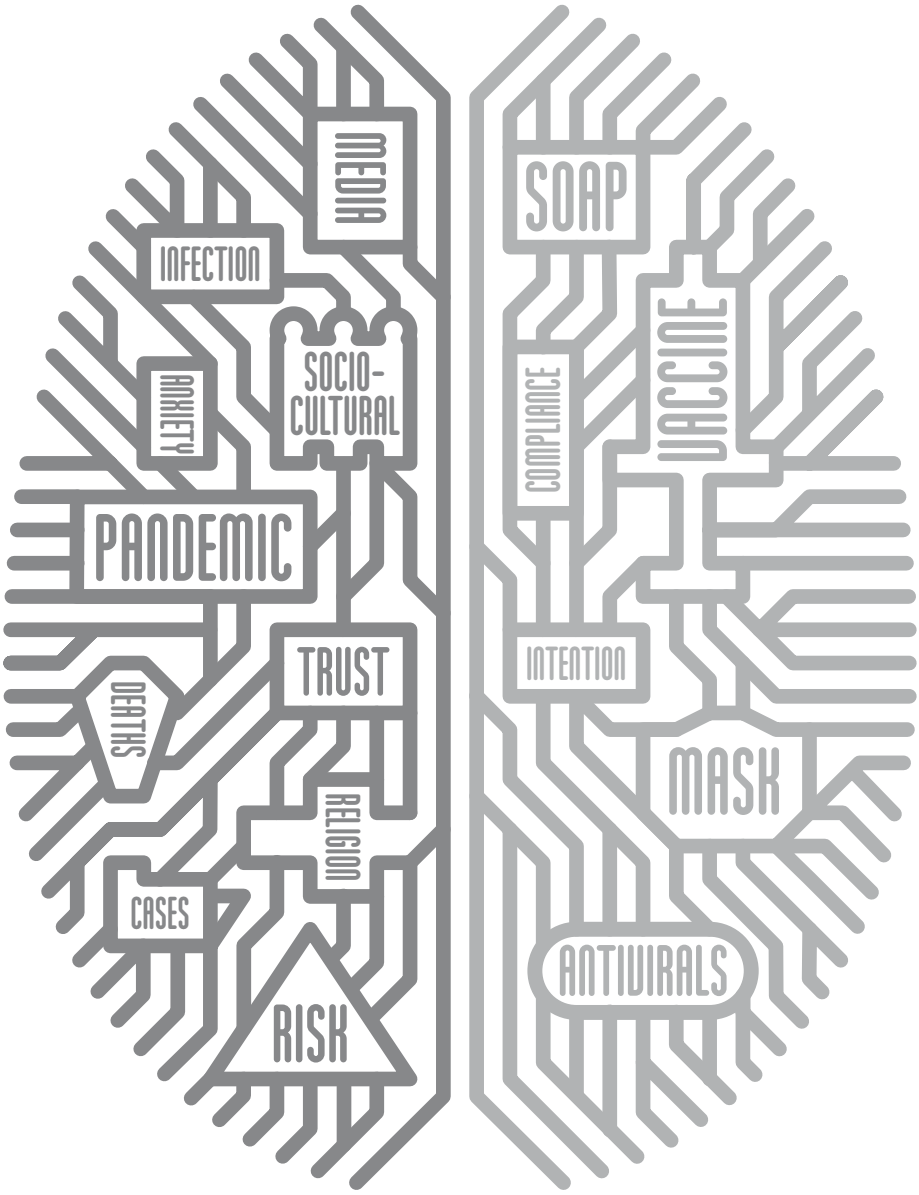


Outbreaks of Emerging Infectious Diseases:

Risk perception and behaviour of the general public

Marloes Bults



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Risk perception and behaviour of the general public

Uitbraken van opkomende infectieziekten:
Risicoperceptie en gedrag van het publiek

Proefschrift

ter verkrijging van de graad van doctor aan de Erasmus Universiteit Rotterdam
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CHAPTER 1
General introduction

General introduction

This thesis focuses on risk perception and behaviour of the public during outbreaks of emerging infectious diseases. It consists of studies on Influenza A (H1N1), Q fever and Lyme disease. These studies were conducted among both the general public and specific risk groups in the Netherlands (including parents of young children and patients with a known aortic aneurysm or vascular prosthesis). This thesis describes trends over time and regional/(sub)national differences in risk perception and behaviour of the public during outbreaks of emerging infectious diseases, as well as determinants of preventive behaviour or strong intention to comply with preventive measures. Furthermore, it provides recommendations for optimising risk communication during future emerging infectious disease outbreaks.

1.1 Emerging infectious diseases

Emerging (or re-emerging) infectious diseases can be defined as infections that have newly appeared in a population or have been known for some time but are rapidly increasing in incidence in a defined period or geographic range [1]. Several factors have been identified as contributors of disease emergence, which are related to the agent (microbial adaptation/change, development of resistant to drugs), host (inhabiting new areas, human behaviour/travelling, human susceptibility, poverty and social inequality) and environment (climate changes, economic development) [2]. More than 60% of emerging infectious diseases are zoonotic and rely on animal populations as reservoirs of infection [3].

1.1.1 Influenza A (H1N1)

Influenza (also known as the flu) is a contagious respiratory illness caused by an influenza virus. Humans can be infected by inhalation of contaminated aerosols, direct contact with infected persons, or contact with contaminated objects [4]. A classic influenza infection is sudden in onset and characterized by fever, headache, cough, sore throat, muscle pain, nasal congestion, weakness and loss of appetite [5]. Most people with influenza recover within a period of a few days to less than two weeks without specific anti-influenza therapy. Children (<5 years of age), older people (≥65 years of age), pregnant women and people with underlying medical conditions are at higher risk of developing influenza-related complications, such as pneumonia, bronchitis and sinus or ear infection, which can lead to hospitalizations or death [6].

About once every 30-40 years, an influenza pandemic occurs when a new strain that has never circulated among people emerges in the population. In the 20th century, there were three influenza pandemics. The Spanish influenza occurred in 1918-1919 and was responsible for over 50 million deaths worldwide [7,8]. The Asian influenza in 1957 counted around 1-4 million deaths, and the Hong Kong influenza in 1968 around 1-2 million deaths [9]. In 2009, a novel flu strain (A/H1N1) caused the first influenza pandemic of the 21st century. For the period April 2009 to August 2010, around 18,500 laboratory confirmed deaths were reported worldwide [10]. However, this number is likely to be only a fraction of the true number of H1N1-associated deaths [11]. As reported in a

study conducted in the Netherlands, the H1N1 pandemic had an moderate overall impact on mortality compared to the 10 preceding seasonal epidemics, but resulted in higher mortality in young children (aged 0-4 years) [12].

For years the World Health Organization (WHO) encouraged countries to prepare pandemic preparedness and response plans to be better prepared to recognize and manage an influenza pandemic [13]. Based on (inter)national preparedness plans, different control strategies were implemented during the H1N1 pandemic in 2009. During the early phase of the pandemic (from end of April to 11th June 2009), most countries implemented control measures according to a "containment/delaying" strategy, which aimed to limit the spread of the H1N1 virus. This strategy included the use of antiviral drugs for early treatment of cases and/or prophylaxis of close contact, isolation of cases, and quarantining of contacts. During the pandemic peak phase (from 11th June to 10th August 2009), most countries were moving to a "mitigation" strategy, which aimed to minimising the impact of the pandemic by recommending personal protective measures, including frequent hand washing, covering the mouth when coughing, and social distancing (e.g. maintaining physical distance from people with flu symptoms and avoiding crowded places). During the post peak phase (from 10th August 2009 to 10th August 2010), the H1N1 vaccine first became available in most countries.

1.1.2 Q fever

Q fever is a zoonotic disease caused by the bacterium Coxiella burnetii. Sheep, goats and cattle are the primary reservoir although other animals have also been identified as a source [14]. Animals shed C. burnetii in milk, urine and faeces, but especially in birth products [15]. C. burnetii can survive for long periods of time in the environment and may be spread by wind and dust [16]. Humans are usually infected by inhalation of contaminated aerosols. The consumption of raw dairy products has also been considered as a potential source, but studies remain inconclusive [17,18]. Infection is asymptomatic in 50-60% of cases. Among persons with clinical symptoms, there is usually an acute onset with fever, headache, and fatigue and frequently an atypical pneumonia or hepatitis [19]. Furthermore, post-Q fever fatigue syndrome has been described following acute Q fever [20]. About 1-5% of all Q fever cases may progress into a chronic infection, often leading to life-threatening endocarditis. Pregnant women and patients with heart valve disorders or immune deficiencies are at higher risk of developing chronic Q fever [15]. Q fever in pregnancy may result in adverse pregnancy outcomes.

Q fever was first described in 1937 among Australian abattoir workers [21]. In Europe, the first cases of human Q fever were reported around 1940 in Bulgaria, Greece and Romania among soldiers as well as the general public [22]. In the Netherlands, the first cases were described in 1956, where it became a mandatory notifiable disease in 1975 [23,24]. In the period 1975-2006, the number of notifications ranged between 1-32 cases per year. The first community outbreak of Q fever in the Netherlands occurred in 2007, in the southern region (Noord-Brabant province). By the end of that year, 168 human Q fever cases were reported [25]. The second wave, in 2008, resulted in exactly 1,000 cases. In 2009, the number of cases reached a peak of 2,357 with alarming increase in Q fever incidence in regions adjacent to Noord-Brabant. Around 20% of the cases were hospitalized and 10% developed chronic Q fever in the period 2007-2009 [26]. Between 2008-2012, 25

patients in the Netherlands died due to Q fever [27]. The implementation of comprehensive (veterinary) measures largely resulted in a decrease of human Q fever cases in the Netherlands (2010: n=504; 2011: n=81; 2012: n=66) [27]. In the past, human Q fever outbreaks had also been described in other (European) countries, but not to the same extent as in the Netherlands [28].

The veterinary measures that were taken by the Dutch government between late 2009 and early 2010 consisted of various components [25]. First, a nationwide hygiene protocol became mandatory for professional dairy goat and dairy sheep farms and 250,000 small ruminants were subject to mandatory vaccination. Second, bulk milk monitoring became mandatory on farms with more than 50 dairy goats and dairy sheep. Third, veterinarians, physicians and the public were informed through targeted mailings, publications and the news media. Fourth, when a dairy goat or dairy sheep farm tested positive for C. burnetii, all inhabitants living within a radius of 5 km of the farm received a letter to inform them of the presence of a Q fever-positive farm in their proximity. Fifth, in 2010, a culling campaign started before the lambing season for pregnant dairy goats and sheep on infected dairy farms. And finally in 2011, patients with specific cardiovascular conditions and patients with aortic aneurysms or vascular prostheses living in high-risk areas were offered Q fever vaccinations.

1.1.3 Lyme disease

Lyme disease (LD), or Lyme borreliosis, is caused by the bacterium Borrelia burgdorferi and is transmitted to humans through the bite of infected blacklegged ticks. About 90% of patients experience a circular red skin rash around the place of the tick bite (erythema migrans) [29,30]. People may also experience fever, headache, fatigue and depression in the first stage of an early-localized infection. In the second stage (early disseminated infection), people can experience additional erythema migrans lesions in other areas of the body, loss of muscle tone on one or both sides of the face, severe headaches and neck stiffness, pain and swelling in the large joints, shooting pains that may interfere with sleep, heart palpitations and dizziness due to changes in the heartbeat. Many of these symptoms will resolve over a period of weeks to months. However, if left untreated, the patient can develop chronic symptoms affecting a wide range of body parts including the heart, joints, brain and nervous system. This period is described as the third stage or late persistent infection [31]. A post-infection fatigue syndrome also described following acute Q fever (see paragraph 1.1.2), can also occur as a result of LD.

LD is the most common tick-borne disease in North Eastern USA and in Europe. In the Netherlands, the incidence of diagnosed patients increased from 6,500 in 1994 to 13,000 in 2001, rising to 17,000 in 2005 and reaching 22,000 in 2009 [32]. LD is now endemic in the Netherlands with an incidence of 133 cases/100,000 inhabitants each year [33]. Similar trends have been observed in other European countries [34].

Most cases of LD can be successfully treated with a few weeks of antibiotics. Besides antibiotic treatment, personal protective measures can be effective to prevent LD [35]. These personal protective measures include wearing protective clothes (i.e. long sleeved shirts and long pants), using insect repellent, performing a full body check within 24 hours after possible tick exposure, and removing ticks promptly.

1.2 Theoretical background

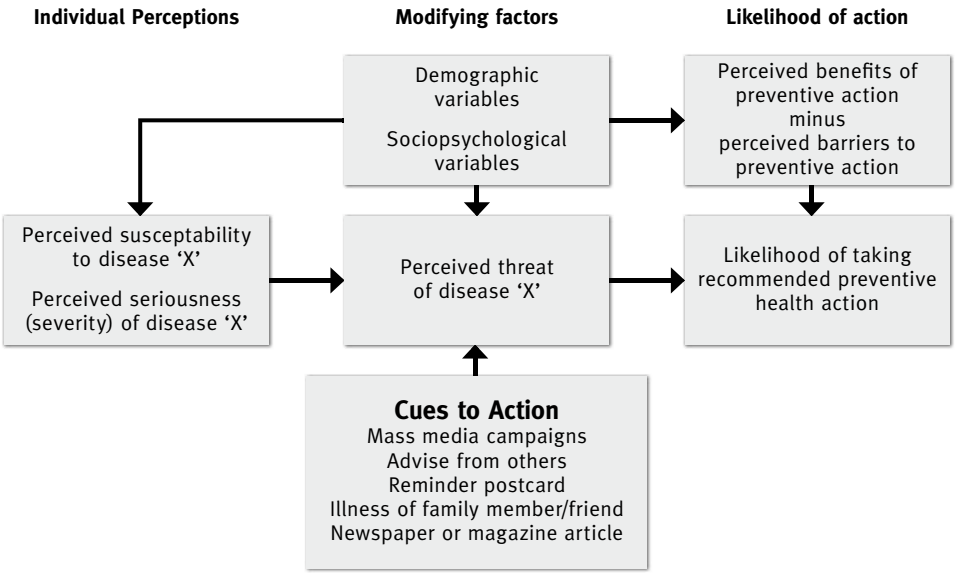
The general public plays an important role in controlling the spread of an infection and minimising the impact of an outbreak by adopting government-recommended preventive measures. Within social science, several theories and models have been developed to explain risk perception and preventive health behaviour. The use of these theories and models when conducting studies on risk perception and behaviour during outbreaks of infectious diseases is strongly recommended because they provide profound insights into perception, behaviour, and their underlying correlations, and greatly facilitate the development of effective public health interventions that counter the impact of an outbreak. A variety of behavioural theories and models has been used in studies on risk perception and preventive behaviour during infectious disease outbreaks, including the Common Sense Model of Self-regulation [36], Extended Parallel Process Model [37], Health Belief Model [38-40], Precaution Adoption Process Model [41], Protection Motivation Theory [42,43], Risk Communication Framework [44], Social Ecological Model [45], Theory of Planned Behavior [46], Theory of Reasoned Action [47,48], Trust and Confidence Model [49], and Trust Determination Model [50].

The Health Belief Model (HBM) is by far the most commonly used theory in health education and health promotion [51]. The Protection Motivation Theory (PMT) is also one of the most cited theories and has been found to be a useful model in predicting health behaviour intentions and behaviours [52,53]. The PMT has been applied to a variety of intervention studies [52,54]. Both theories share the idea that motivation towards protection results from a perceived threat and the desire to avoid the potential negative outcome. Furthermore, both theories includes perceived effectiveness (or response efficacy) and a cost-benefit analysis component in which the individual weighs the costs of taking the preventive measure against the expected benefits. Although the HBM and PMT have similarities, there are some differences [55]. For example, the way in which the two models are organised differs. The HBM is organized as a catalogue of variables contributing to behaviour, whereas the PMT includes two cognitive processes (the threat appraisal and coping appraisal process). Furthermore, the PMT includes one's belief in the ability to perform the preventive measure (self-efficacy) which is warranted as an important determinant of health behaviour [56]. It was recognised that using constructs found in both models might have additional value. Therefore, studies described in this thesis were based on an integrated model to explain health behaviour, which included constructs from both the HBM and PMT.

1.2.1 The Health Belief Model

The HBM was first developed in the 1950s in response to the failure of a free tuberculosis screening program [38,39]. The HBM was further developed by Rosenstock and Becker in the 1970s and 1980s to explain and predict acceptance of health and medical care recommendations [57]. The main constructs of the HBM are: perceived susceptibility to and perceived seriousness/severity of a disease; and perceived benefits of and perceived barriers to preventive action (*Figure 1*). Perceived seriousness is defined as the individual's belief about the seriousness or severity of a disease and its consequences. Perceived susceptibility is described as the perception of the chance of getting a disease. These two constructs together represent perceived threat. Perceived benefits

Figure 1 The Health Belief Model [40]

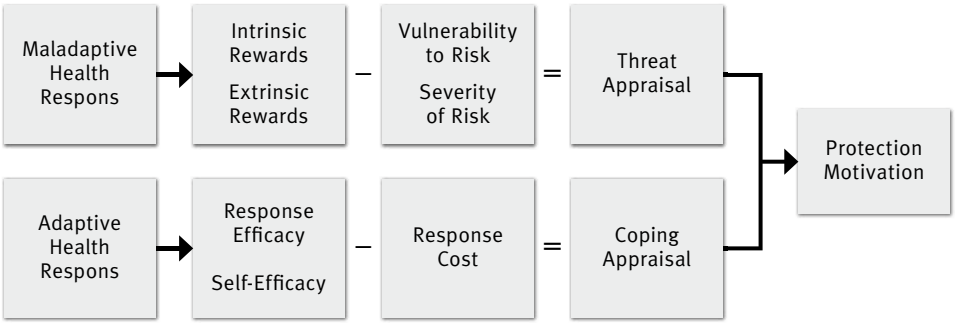


describe one's belief in the efficacy of the recommended action to reduce the risk or impact of the disease. Perceived barriers describe one's belief about the tangible and psychological costs of the recommended action. More recently, other construct have been added including demographic and socio-psychological variables and cues to action (strategies to activate "readiness"). Although the HBM has been one of the most widely used conceptual frameworks in health education and health promotion, it does have some limitations. The constructs are broadly defined and therefore different operationalisations may not be strictly comparable. The relationship between constructs is not well understood, especially the influence of cues to action on (the likelihood of) action. Finally, the role of emotions (such as fear) and the influence of the social environment are absent.

1.2.2 The Protection Motivation Theory

The PMT was originally developed to explain the effects of fear-arousing health threat communications or 'fear appeals' [42]. The model was revised to include reward and self-efficacy components [58]. The PMT distinguishes two possible health responses: the adaptive health response (behaviour that protects one's health) and the maladaptive health response (behaviour that does not protect one's health) (*Figure 2*). The PMT is organised along two cognitive processes: the threat-appraisal process and the coping-appraisal process. Threat appraisal is the individual's estimation of the likelihood of contracting a disease (perceived vulnerability) and of the seriousness of a disease (perceived severity). Coping appraisal is the individual's expectancy that carrying out the recommendation can remove the threat (response efficacy) and belief in ability to perform the preventive measure (self-efficacy). These four constructs have received the most empirical attention with regard to motivation to protect oneself against a health threat [43,59]. Other constructs included in the PMT are: intrinsic (e.g. pleasure) and extrinsic

Figure 2 The Protection Motivation Theory [43]



(e.g. social approval) rewards and response costs or barriers. The PMT also has some limitations. Most criticism of PMT concerned its overemphasis on cognitive processes and critics suggest that the mediating role of emotion (especially fear) on protection motivation should be considered more thoroughly. Furthermore, not all personal factors (like demographic variables, individual's knowledge and prior experience) and environmental variables (like influence of social environment, i.e. social norm/pressure) that could impact protection motivation are identified [52].

1.3 What is already known?
Risk perception and behaviour during the SARS epidemic and H5N1 avian influenza outbreaks

In early 2003, Severe Acute Respiratory Syndrome (SARS) caused by a corona virus emerged in southern China and rapidly spread to more than 30 countries. The SARS epidemic resulted in around 8,000 cases with a case fatality rate of 9.6% [60]. Since 2003, there were also ongoing outbreaks of H5N1 avian influenza among humans. From 2003 to 2009, 468 human H5N1 avian influenza cases, including 282 deaths, were reported in 15 countries [61]. In the Netherlands, no SARS or human H5N1 avian influenza cases have been diagnosed. As described above, the general public plays an important role in controlling the spread of an infection and minimising the impact of an outbreak by adopting government-recommended preventive measures.

During the SARS epidemic and H5N1 avian influenza outbreaks, studies were conducted on risk perception and behavioural responses of the public. Most of these studies consisted of a single cross-sectional survey measuring perception and behaviour at one point in time, or only included inhabitants of one country or region [62-77]. However, a few studies consisted of multiple cross-sections or follow-up surveys designed to analyse trends over time [78-81] or included inhabitants of different countries or regions designed to identify regional or (sub-)national differences [82-91]. A number of studies have been conducted to identify determinants of SARS or H5N1 avian influenza preventive behaviour [62,63,66-68,71,73,78,80,87,91-101]. Bish and Michie (2010) conducted a review of these studies [102].

1.3.1 Time trends

Lau, Yang, Tsui and Kim (2003) studied perception and behaviour among the general public in Hong Kong in response to the SARS epidemic [78]. Ten cross-sectional survey rounds were conducted during both the initial/escalating phase, when the number of SARS cases increased (March-April 2003), and during the second phase, when the number of cases decreased (April-May 2003). During the initial phase, increasing trends were observed in perceived efficacy of wearing facemask, taking hygienic measures (frequent hand washing, home disinfection) and avoidance behaviour (avoiding public transport and crowded public places such as the cinema). Notably, the percentage of respondents who took hygiene measures and avoided public places rose dramatically during this period. However, during the second phase, perceived susceptibility and feelings of worry/fear of contracting the virus decreased. Furthermore, perceived efficacy of avoidance behaviour and the percentage of respondents who took preventive measures decreased during this phase. Wong and Tam (2005) conducted two surveys among medical students during the first SARS outbreak (2003) and one year after the epidemic had ended (2004) and results describe a significant improvement in compliance with hand hygiene practices [80].

Lau, Tsui, Kim, Chan and Griffiths (2010) also monitored changes in behavioural and emotional responses to human H5N1 avian influenza among Hong Kong adults [79]. Six cross-sectional studies were conducted over a 28-months period (2005-2008), during which no human cases were reported in Hong Kong. Decreasing trends were observed in perceived severity and perceived susceptibility of contracting H5N1, worry about a large-scale outbreak, and intention to increase frequency of hand washing, avoid crowded places and use facemasks in public areas. De Zwart, Veldhuijzen, Richardus and Brug (2010) conducted seven cross-sectional surveys in the Netherlands in 2006 and 2007 [81]. They described that perceived severity was stable over time. Levels of knowledge and perceived vulnerability of avian influenza slightly decreased over the study period. Furthermore, the percentage of respondents who had taken preventive measures (improved hygiene, avoided affected areas and crowded places, getting influenza vaccination, and buying antiviral drugs and mouth mask) increased between March and June 2006 and remained stable afterwards.

As reported above, different patterns in risk perception and behaviour of the public were observed during the SARS epidemic and H5N1 avian influenza outbreaks. However, the numbers of studies are too limited to draw firm conclusions.

1.3.2 Regional differences

Leung et al. (2004; 2009) reported psycho-behavioural responses to SARS in Hong Kong and Singapore in 2003 [87,88]. Although both cities were centres of the epidemic, Hong Kong had experienced a much more dramatic outbreak compared to Singapore. The studies show that knowledge about route of transmission, perceived severity, perceived vulnerability, anxiety levels and the percentage of those who performed protective measures (such as hygiene measures and using face masks) were higher among Hong Kong respondents compared to Singaporean respondents. Vartti et al. (2009) conducted a study to compare SARS knowledge, perception and behaviour among the general public in Finland and the Netherlands in 2003 [89]. In the Netherlands, no probable SARS cases were reported, whereas in Finland two people were initially treated as probable SARS cases.

They concluded that Finns were more knowledgeable and worried about SARS, but had lower perceived risk and self-efficacy beliefs about preventing SARS compared to the Dutch respondents. However, more Finns wore a facemask, washed hands more frequently and tried to sleep more. Furthermore, Blendon, Benson, DesRoches, Raleigh and Taylor-Clark (2004) conducted thirteen surveys among inhabitants of 3 geographic areas which had substantial differences in the number of SARS cases. They concluded that even in areas with a low number of cases, there was extensive public response to the SARS threat [91].

De Zwart et al. (2007; 2009) conducted a study of SARS and avian influenza risk perception in five EU-countries (Denmark, the Netherlands, UK, Spain and Poland) and three east Asian areas (Singapore, the Chinese province Guangdong and Hong Kong) in 2005 [85,86]. The study concluded that SARS and avian influenza were perceived as more severe in Europe whereas levels of knowledge, response efficacy and self-efficacy were significantly higher in Asia. Voeten et al. (2009) studied SARS- and avian influenza-related health beliefs among Chinese communities and the general population in the UK and the Netherlands in 2005 and 2006 [84]. They concluded that perceived severity and perceived threat was lower among Chinese communities compared to the general population. Knowledge of SARS, perceived efficacy and self-efficacy was, however, higher among the Chinese communities compared to the general population.

Rudisill, Costa-Font and Mossialos (2012) described results from the Eurobarometer survey that was conducted in 2006 [83]. Almost 30,000 residents of 27 EU countries and two candidate countries (Croatia and Turkey) participated in this study. At this point, positive human H5N1 avian influenza cases had only been reported in Turkey. They found that people were more likely to change their behaviour if there are human cases of H5N1 virus in or bordering their country of residence. Peltz, Avisar-Shohat and Bar-Dayan (2007) conducted a study in Israel to compare the emotions, interest, sense of knowledge and compliance, of the population in the affected area (no human cases, but settlements were birds were infected with H5N1) with the nationwide general population [90]. Compliance with government advised preventive measures, including baking omelette properly, buying eggs and poultry only in authorized groceries, checking veterinary certificate, and confirming sealed packing when buying eggs, did not significantly differ between the affected area and the nationwide population. However, the interest in bird flu and sense of knowledge were significant higher in the affected area, whereas misconceptions of a high human to human transmission, level of stress and fear were significant lower in the affected area compared with the nationwide population. Liao et al. (2009) conducted a survey among adults living in the Chinese city of Guangzhou and Hong Kong in 2006 [82]. Both cities were comparable in SARS and H5N1 cases, wet market traditions and cultural characteristics. However, Guangzhou had a high-intensity poultry and pig farming and high human densities. In Hong Kong, the first human avian influenza case was identified in 1997 and more extensive control measures were implemented (as strict wet market regulation and hygiene measures).They concluded that perceived overall risk and perceived self/family risk from buying live poultry were higher in Guangzhou.

As the above studies describe risk perception and behaviour of the public are not always in line with the actual risk (epidemiology) and varies between inhabitants of different regions/countries.

1.3.3 Determinants of preventive behaviour

Bish and Michie (2010) conducted a review of determinants of protective behaviour, which included studies on SARS and H5N1 avian influenza [102]. They found that people who were older, female or higher educated more often performed preventive behaviour like hand washing, respiratory hygiene, wearing face mask and avoiding crowded places [63,66-68,72,78,87,95,97,98,101]. Although the majority of the studies support these findings, some studies remained inconclusive for one or more of these demographic variables [62,68,94,95,98,100,101].

Greater perceived vulnerability was found to be positively associated with taking preventive measures against SARS or H5N1 avian influenza, like hand washing, good personal hygiene, disinfecting the home, mask wearing, avoidance behaviour, and compliance with quarantine restrictions [62,66,78,87,92,94,95,98-101]. Higher levels of perceived severity were also positively associated with wearing masks and avoidance behaviour [63,72,78,94,95]. A positive relation has also been found between the perceived efficacy of mask wearing, frequent hand washing, disinfecting the home, influenza vaccination and avoidance behaviour, and actually carrying out this behaviour [63,71,78,94,95,98]. Furthermore, persons with higher levels of anxiety are more likely to adopt recommended preventive measures like hand washing, cough hygiene and mask wearing [66,67,87,97]. However, some studies remained inconclusive for one or more of these perceptions [66-68,71,97,99].

The balance of the evidence described above has shown that significant determinants of taking measures to prevent SARS and/or H5N1 avian influenza are being older, female, higher educated, and higher levels of perceived severity, susceptibility and efficacy beliefs.

1.4 Risk communication during outbreaks: Importance of studies on risk perception and behaviour of the public

Risk communication is defined as an interactive process of exchange of information and opinion on risk among risk assessors, risk managers, and other interested parties [103]. The term crisis communication is associated more with emergency management and the need to inform and alert the public about an event [103,104]. Although some differences in definition exist, the terms risk communication and crisis communication are often used interchangeable in the literature.

Risk (or crisis) communication is considered a key element in encouraging the public to comply with government-advised preventive measures [104,105]. The WHO created guidelines and encouraged countries to develop as part of the pandemic preparedness and response plans, communication strategies that include detailed information on what to communicate, how to do it, to whom and by whom [105]. Different risk communication models have been developed describing how risk information is processed and the influence of risk information on risk perception and preventive behaviour of the public. Covello, Peters, Wojtecki and Hyde (2001) identified four theoretical models including the risk perception model, mental noise model, negative dominance model and trust

determination model [104]. The risk perception model identified 15 risk perception factors that have direct relevance to risk communication, including voluntariness, controllability, familiarity, equity, benefits, understanding, uncertainty, dread, trust in institutions, reversibility, personal stake, ethical/moral nature, human versus natural origin, victim identity and catastrophic potential [104,106]. For example, risks perceived as unfamiliar are less readily accepted and are perceived as greater than risks perceived to be familiar. The mental noise model notes that when people are in a state of high concern because they perceive a significant threat, their ability to process information effectively and efficiently is severely impaired [104,107]. The negative dominance model describes the processing of negative and positive information in high-concern situations [104]. It states that communication containing negative information tends to receive closer attention, is remembered longer and has greater impact than positive messages. One of the practical implications of this model is that negative messages should be counterbalanced by a larger number of positive or solution-oriented messages. The final model is the trust determination model. Building trust and public confidence is a key principle for effective risk communication [50,104,108,109]. As stated by the WHO, the aim of effective communication during an outbreak is "to communicate with the public in ways that build, maintain or restore trust" [105]. The trust determination model describes the different factors that are important for building trust and public confidence, including caring and empathy, dedication and commitment, competence and expertise, and honesty and openness.

Besides theoretical models, practical tools have been also developed to facilitate risk communication about communicable diseases. Examples are the WHO communication guidelines and the Crisis Emergency and Risk Communication toolkit (CERC) [105,110,111]. The CERC toolkit provides materials as books, videos and online-training. The CERC toolkit also provides information on risk communication regarding five phases:

1 pre-crisis phase (risk messages, warnings, preparations);

2 initial event phase (uncertainty reduction, self-efficacy, reassurance);

3 maintenance phase (ongoing uncertainty reduction, self-efficacy, reassurance);

4 resolution phase (updates regarding resolution, discussions about cause and new risks/ new understanding of risks);

5 evaluation phase (discussion of adequacy of response, consensus about lessons learned and new understanding of risks) [110].

The majority of the general public form their risk perceptions based on information provided by media [112]. Therefore, the CERC toolkit describes how communicators have to deal with the media.

Effective risk communication includes a *dynamic* and *interactive* process involving exchanges between *different professional groups* and *other interesting parties*, including the public [105]. Effective risk communication encourages involvement of the public in the process of controlling an infectious disease outbreak. Although government and other

health institutes are likely to make decisions based on actual risk or other factors (like economics), the general public relies mainly on its perception of disease severity and vulnerability. Surveillance of perception and behaviour of the public is important and provides useful information for tailoring risk communication and strategies for instructing and motivating the public during outbreaks of infectious diseases, but is also useful in building public trust in health authorities and preventing misconceptions [113,114]. This is also in line with the work of Slovic (1987) who note that "risk communication efforts are destined to fail unless they are structured as a two-way process. Each side, expert and public has something valid to contribute. Each side must respect the insights and intelligence of the other" [106].

1.5 Research questions and outline of this thesis

This thesis answers three research questions.

1 *What are common patterns in trends over time in risk perception and preventive behaviour of the general public during outbreaks of emerging infectious diseases?*

2 *What are important regional differences in risk perception and preventive behaviour of the general public during outbreaks of emerging infectious diseases?*

3 *What are determinants of preventive behaviour or strong intention to comply with preventive measures?*

In **Chapter 2**, the results are described of two cross-sectional and one follow-up survey conducted during the 2009 Influenza A (H1N1) pandemic among the general public in the Netherlands. These studies were conducted in April/May, June and August 2009. We report trends over time in risk perception, feelings of anxiety, and behavioural responses. This chapter also provides information on determinants of taking preventive measures and of having a strong intention to comply with government-advised preventive measures in the future. **Chapter 3** describes results of the last (fourth) survey that we conducted during the 2009 Influenza A (H1N1) pandemic, in November 2009. This paper builds further on the findings described in Chapter 2. This chapter also describes determinants of practising better hygiene (including washing hands more often and using tissues when coughing and sneezing) and intention to be vaccinated.

In **Chapter 4**, we describe determinants among parents of acceptance or declination of H1N1 vaccination for their child, such as the reasons for (non-)acceptance, risk perception, feelings of doubt and regret, influence of the social network, and information-seeking behaviour. To optimise vaccination rates in future vaccination campaigns, this chapter also provides recommendations for risk communication.

Chapter 5 describes the results of a systematic literature search on perception and behaviour of the public during the Influenza A (H1N1) pandemic with a special focus on 1) trends over time and 2) differences between countries/regions.

In **Chapter 6**, the results of one cross-sectional (2009) and two follow-up surveys (2010, 2012) regarding Q fever in the Netherlands are described. This study describes trends over time and regional differences in perception and behaviour among the public regarding Q fever in the Netherlands. In **Chapter 7**, we describe patient determinants for accepting Q fever vaccination, including reasons for acceptance, risk perception, feelings of doubt, social influence, information-seeking behaviour, preventive measures taken, and perception regarding received information and governmental action.

Chapter 8 describes a study on perception and protective behaviour of the public regarding Lyme disease. This study describes determinants of wearing protective clothes and checking skin after being outdoors to prevent tick bites. It also provides several implications for the development of Lyme disease prevention programs.

In **Chapter 9**, the main findings are summarised and the research questions are answered and discussed in relation to the international literature. This thesis concludes with a summary in English and Dutch.

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CHAPTER 2

Perceived risk, anxiety, and behavioural responses of the general public during the early phase of the Influenza A (H1N1) pandemic in the Netherlands:

results of three consecutive online surveys

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Abstract

Background
Research into risk perception and behavioural responses in case of emerging infectious diseases is still relatively new. The aim of this study was to examine perceptions and behaviours of the general public during the early phase of the Influenza A (H1N1) pandemic in the Netherlands.

Methods
Two cross-sectional and one follow-up online survey (survey 1, 30 April-4 May; survey 2, 15-19 June; survey 3, 11-20 August 2009). Adults aged 18 years and above participating in a representative Internet panel were invited (survey 1, n=456; survey 2, n=478; follow-up survey 3, n=934). Main outcome measures were 1) time trends in risk perception, feelings of anxiety, and behavioural responses (survey 1-3) and 2) factors associated with taking preventive measures and strong intention to comply with government-advised preventive measures in the future (survey 3).

Results
Between May and August 2009, the level of knowledge regarding Influenza A (H1N1) increased, while perceived severity of the new flu, perceived self-efficacy, and intention to comply with preventive measures decreased. The perceived reliability of information from the government decreased from May to August (62% versus 45%). Feelings of anxiety decreased from May to June, and remained stable afterwards. From June to August 2009, perceived vulnerability increased and more respondents took preventive measures (14% versus 38%). Taking preventive measures was associated with no children in the household, high anxiety, high self-efficacy, more agreement with statements on avoidance, and paying much attention to media information regarding Influenza A (H1N1). Having a strong intention to comply with government-advised preventive measures in the future was associated with higher age, high perceived severity, high anxiety, high perceived efficacy of measures, high self-efficacy, and finding governmental information to be reliable.

Conclusion
Decreasing trends over time in perceived severity and anxiety are consistent with the reality: the clinical picture of influenza turned out to be mild in course of time. Although (inter)national health authorities initially overestimated the case fatality rate, the public stayed calm and remained to have a relatively high intention to comply with preventive measures.

Background

At the end of April 2009, an outbreak of a new Influenza A (H1N1) virus occurred in Mexico and the United States, spreading rapidly to other countries worldwide. The Influenza A (H1N1) virus has became the dominant influenza strain in most parts of the world. Up to January 2010, around 14000 deaths related to Influenza A (H1N1) were reported worldwide [1]. The virus can cause very severe and fatal illness, but the majority of patients experience mild symptoms comparable to the common seasonal influenza. Important differences with the seasonal flu exist. For example, most severe cases and deaths have occurred in adults under 50 years of age, and severe respiratory failure has been reported more frequently in young and healthy persons [2]. When the WHO raised the pandemic alert to phase 6, the focus shifted towards delaying viral spread through population-based measures, such as hand and respiratory hygiene, and voluntary isolation of symptomatic persons [3-5].

In the Netherlands, a new vaccine against the Influenza A (H1N1) virus became available for specific risk groups in November 2009 [6]. Nevertheless, during the 2009 Influenza A (H1N1) pandemic, behavioural responses of the general public were very important in limiting spread of the virus. Compliance with preventive measures, such as non-medical interventions, antiviral treatment, and vaccination, is dependent upon the willingness and ability of the general public. Compliance with preventive measures is not self-evident. During the SARS epidemic in 2003, the use of face masks was low among adults in Hong Kong and air travellers with influenza-like symptoms [7,8]. In the Netherlands, during an outbreak of avian Influenza among poultry in 2003, large groups of the population did not adhere to personal protective measures or instructions regarding prophylaxis [9].

Surveillance of perceptions and behavioural responses of the general public during pandemics provides useful information for health risk communication and achieving successful changes in public behaviour [10,11]. In recent years, a number of studies have been published on risk perception and public responses in case of a pandemic influenza [12-19]. These studies were conducted prior to the occurrence of the 2009 Influenza A (H1N1) pandemic, in times when pandemic influenza was not regarded as a high threat and information was based on hypothetical scenarios. During the 2009 influenza pandemic a number of studies have been conducted among the general public on risk perception of the Influenza A (H1N1) and intention to take preventive measures [20-22]. These studies consisted of a single, cross-sectional survey. In the present study we aimed to examine perceived risk, feelings of anxiety, and behavioural responses of the Dutch general public related to the outbreak of Influenza A (H1N1) over a period with changing risks and publicity. The first objective of this study was to identify trends over time in risk perception, feelings of anxiety, and behavioural responses (survey 1-3). The second objective was to assess factors significantly associated with taking preventive measures and strong intention to comply with government-advised preventive measures in the future (survey 3).

Methods

Timing of the three surveys related to the course of the Influenza A (H1N1) outbreak
The first survey started on 30 April 2009, when the first case of Influenza A (H1N1) was confirmed in the Netherlands. At that time there were 27 confirmed Influenza A (H1N1) cases in eight different European Union (EU) countries. The first survey ended on 4 May, when the number of cases in the EU had increased to more than 100, including 15 human-to-human transmissions [23,24]. The second survey started on 15 June 2009, when there was sustained transmission of the Influenza A (H1N1) virus in several countries and the WHO raised the pandemic alert status to phase 6, characterized by human-to-human spread and community-level outbreaks in more than one WHO region. At that time, there were confirmed cases in 82 countries, including 167 deaths. In the Netherlands, the number of confirmed cases had increased to 60. The second data collection period ended on 19 June; when there were more than 200 deaths worldwide [25,26]. The follow-up survey took place from 11 to 20 August 2009, when the Netherlands counted 1021 confirmed cases, including the first fatal case [27]. On 20 August, the total number of reported and confirmed pandemic influenza cases in the world was 248941, including 2430 deaths [27,28].

Participants
At three different time points, an online survey was filled out by a representative Internet panel, named the Flycatcher panel (www.flycatcher.eu). This panel consists of people from the Dutch general public who volunteer to participate in online questionnaire surveys. The Flycatcher panel consists of 20,000 members. The distribution of demographic variables (gender, age, region, and level of education) of the panel members is comparable to the general Dutch population. The panel meets high quality requirements and is ISO-certified. For the first and second survey, independent random samples were drawn of approximately 1000 panel members aged 18 years and older. All respondents of the first and second survey were invited to participate in the third (follow-up) survey. Panel members who participated in the first or second survey but did not respond to the follow-up survey (n=255) were excluded from further analyses. Sampled panel members were invited to participate in this study by sending an email with an Internet link. The surveys were online for a period ranging from 5 to 10 days. Panel members received 1.50 Euro in credits for completion of the survey, which could be exchanged for gift vouchers.

The nature of this general Internet-based survey amongst healthy volunteers from the general population does not require formal medical ethical approval according to the Dutch law [29].

Online questionnaire
An online questionnaire was developed based on an existing questionnaire used in studies on risk perception and precautionary behaviours of the general public during outbreaks of SARS [30] and avian Influenza [31]. The questionnaire was based on an integrated model to explain health behaviour, including constructs from the Protection Motivation Theory (PMT) [32] and the Health Belief Model (HBM) [33]. These theories were applied because risk perception is one of the central constructs. Risk perception is specified as a combination of perceived severity (a person's belief on how serious

contracting the illness would be for him/her) and perceived vulnerability (a person's perception of the chance that he/she will contract the disease). Furthermore, the PMT has two other key constructs besides risk perception, namely response efficacy (a person's belief in the effectiveness of the preventive measure) and self-efficacy (a person's level of confidence in his/her ability to perform the preventive measure). The PMT states that a high risk perception will only lead to preventive behaviour if response efficacy and self-efficacy are also high. To examine perceived risk and factors associated with taking preventive measures during the 2009 influenza pandemic we included the following constructs: perceived severity of and vulnerability to Influenza A (H1N1), perceived efficacy of preventive measures, and a persons' ability (self-efficacy) and intention to take measures. Participants were asked about preventive measures against the new flu, namely: 'avoiding crowded places'; 'practicing better hygiene (washing hands more frequent, using tissues when coughing or sneezing)'; 'avoiding persons with influenza like illness'; 'wearing face mask'; 'seeking medical advice with the onset of flu symptoms'; 'taking antiviral medication (i.e. Tamiflu)'; and 'staying home from school or work'. In the second and third surveys an additional measure was included, namely 'getting vaccinated with a new vaccine'. Questions about feelings of anxiety for Influenza A (H1N1) were also added [34]. Maladaptive responses are behaviours which does not protect one's health. Maladaptive responses may result in a lack of following advice from public health authorities. In the second and third surveys maladaptive response items were included and phrased as statements on underestimation, fatalism, and avoidance. The questionnaire concluded with items on amount of information received on Influenza A (H1N1), attention paid to the information, reliability and sufficiency of information provided by the government, information needs, and preferences for ways of communication during the further course of the Influenza pandemic. Knowledge was examined by statements concerning the modes of transmission, infectiousness, feasibility of symptoms, and fatality of Influenza A (H1N1). The questionnaire was similar across the three survey rounds (Additional file 1). For knowledge, a summary score was created based on the number of correct answers and dichotomized as 0 (<4 items correct) or 1 (≥4 items correct). For all other constructs with 2 or more items, Cronbach's alpha was calculated. The Cronbach's alpha of the constructs ranged from 0.6 to 0.9. Therefore, a summary score was formulated by adding up the scores of the individual items, and dichotomized on the median.

Analysis

Time trends were analyzed using the Chi-square test for differences between surveys 1 (May 2009) and 2 (June 2009). Survey 3 of August 2009 was divided into 3.1 (follow-up of survey 1), and 3.2 (follow-up of survey 2); the Mc-Nemar test was used for analyzing differences between surveys 1 and 3.1 and between 2 and 3.2. Univariate and multivariate logistic regression analyses were performed to identify factors significantly associated with taking one or more preventive measures and strong intention to comply with government-advised preventive measures in the future. For the regression analyses we used data from survey 3 (August 2009), when a substantial amount of people took preventive measures (resp. 40%) compared to survey 1 and 2 (resp. 11% and 14%). For the multivariate regression analyses, all factors with a p-value <0.1 in the univariate analysis were entered in the multivariate model, and removed one-by-one (starting with the most insignificant one etc.) until only statistically significant predictors ($p<0.05$) remained.

Results

Response rates and demographic characteristics
During the first survey in May 2009, 973 panel members were invited and 59% completed the online questionnaire. During the second survey in June 2009, 981 panel members were invited with a response rate of 63%. Of the 1192 respondents from the first two rounds who were invited for the follow-up survey in August, 79% completed the questionnaire.

Demographic characteristics of respondents are listed in *Table 1*. Overall, there were no significant differences between surveys. Focusing on survey 3, mean age was 51 years (range 19-89 years) and most respondents (92%) were of Dutch origin. Thirty-eight percent had a lower education (i.e. primary education, lower general or lower vocational education or less), 36% an intermediate (i.e. secondary general or vocational education), and 26% a higher education (i.e. higher professional education or university). The majority of respondents were employed. About three quarters were married or cohabitating and in 27% of the households there were one or more children under 18 years. Compared to the general Dutch population *(Table 1)*, the respondents were older, more often of Dutch origin, and more often unemployed/retired.

Time-trends in perceived risk, feelings of anxiety, and behavioural responses
The level of knowledge regarding Influenza A (H1N1) was generally high *(Table 2)*. The percentage of respondents who answered 4 or more out of 6 items correctly increased significantly over time during the survey period, from 88% in May to 95% in August 2009 (for the survey in August, we refer to the results of survey 3.2). Only knowledge regarding the availability of a vaccine (which was not available before November 2009) decreased.

The percentage of respondents who reported a high perceived severity of Influenza A (H1N1) decreased from 80% in May to 39% in August 2009, whereas a high perceived vulnerability increased from 5% in June to 15% in August *(Table 2)*. Feelings of anxiety decreased from May to June, and remained stable afterwards. The perceived efficacy of preventive measures was highest for practicing better hygiene, avoiding regions with the new flu or persons with influenza-like symptoms, and seeking medical advice with the onset of flu symptoms; the percentage who perceived these measures to be effective ranging from 66% to 89% in August 2009. At the same time respondents felt confident to practice these preventive measures (perceived self-efficacy) ranging from 66% who felt confident to avoid persons with influenza-like symptoms to 88% who felt confident to practice better hygiene. The intention to comply decreased significantly over the three surveys for four out of seven preventive measures. The highest intention to comply was reported for practicing better hygiene and seeking medical advice, the lowest for staying home from school or work and wearing a face mask. The percentage of respondents who were likely to get vaccinated against Influenza A (H1N1) (when advised by the government) decreased from 77% in June to 63% in August.
Over time, more respondents agreed with the statement that 'the threat of the new flu was exaggerated by the media or government' (35% June, 58% August) and that 'it would not be as bad as predicted' (28% June, 49% August). Also, a larger number of respondents were in agreement with the statement 'we just have to accept it', increasing from 24% in May to 47% in August.

Table 1 Demographic characteristics of respondents, survey 1, 2 and 3

Characteristics	Survey 1 30 April-4 May (n = 456)	Survey 2 15-19 June (n = 478)	Survey 3 follow-up 11-20 August (n = 934)	Data Statistics NL 1-1-2009
Sex				
Male	52%	52%	52%	50%
Female	48%	49%	48%	51%
Age				
18-29 years	13%	12%	12%	18%
30-49 years	33%	40%	36%	37%
Above 50 years	55%	49%	52%	44%
Ethnicity				
Dutch	90%	92%	92%	80%
Non-dutch	10%	8%	8%	20%
Education				
Low	40%	39%	38%	33%
Intermediate	38%	38%	36%	41%
High	22%	23%	26%	25%
Employment status				
Employed	-	61%	57%	76%
Unemployed/Retired	-	40%	43%	24%
Marital status				
Single	-	17%	19%	
Married/Cohabitating	-	76%	73%	
Divorced/Widowed	-	7%	7%	
Children <18 years in household				
Yes	-	27%	27%	
No	-	73%	73%	

'-' *data not collected in survey 1.*

The amount of received information about Influenza A (H1N1) decreased significantly between May and June and increased between June and August 2009, with the percentage of respondents who received (very) much information increasing from 37% to 48%. Information from the government was found less reliable over time; 62% found the information of the government reliable in May; in August 2009 this value decreased to 45%. In August 2009, 70% reported a need for more information, mainly regarding details on the symptoms of Influenza A (H1N1) (30%), how to prevent infection (27%), and how it can be treated (16%) (data not shown). The preferred method for receiving this information was television (47%), Internet (36%), and newspapers (36%). The respondents preferred this information to be given by local or national health institutes or their general practitioner.

There was an increase in the percentage of respondents who had taken any preventive measure between June (14%) and August 2009 (38%). Practicing better hygiene was

Table 2 Trends over time in risk perception, anxiety and behavioural responses

	Survey 1 30 April-4 May (n = 456)	
Knowledge		
1. The new flu is caused by a new influenza virus (correct)	74%	
2. A vaccine is available against the new flu (incorrect)[§]	50%	
3. The new flu can be transmitted by human-to-human contact (correct)	97%	
4. People died from the new flu (correct)	97%	
5. The new flu can be transmitted through eating pork (incorrect)	91%	
6. Symptoms of the new flu are visible (incorrect)	81%	
7. A flu pandemic occurs once in 10-50 years (correct)	-	
Summary score (4 or more correctly answered)	88%	
Perceived severity (scale 1-5)		
1. Severity of the new flu (score 4-5, severe-very severe)	80%	
2. Severity of getting the new flu coming year (score 4-5, severe-very severe)	70%	
3. The new flu is very harmful for my health (score 4-5, mostly-totally agree)	-	
Summary score items 1-2 (high) – Chronbach's alpha 0.8	64%	
Perceived vulnerability (scale 1-5)		
1. Perceived susceptibility (score 4-5, quite-very susceptible)	18%	
2. Perceived chance of getting infected next year (score 4-5, likely-very likely)	5%	
3. Perceived chance of getting infected compared to others (score 4-5, more-much more)	6%	
Summary score (high) – Chronbach's alpha 0.6	15%	
Perceived anxiety (scale 1-5)		
1. Worried about the new flu (score 4-5, worried-very worried)	36%	
2. Fear for the new flu (score 4-5, scared-very scared)	16%	
3. Thinking about the new flu (score 4-5, often-very often)	27%	
Summary score (high) – Chronbach's alpha 0.8	61%	
Perceived efficacy (scale 1-5; certainly not-certainly)		
1. Keep away from crowded places (score 4-5)	55%	
2. Practice better hygiene (score 4-5)	80%	
3. Avoid regions/persons[¥] with new flu (score 4-5)	82%	
4. Wear face mask (score 4-5)	34%	
5. Seek medical advice with the onset of flu symptoms (score 4-5)	78%	
6. Take antiviral medication (score 4-5)	37%	
7. Stay home from school or work (score 4-5)	18%	
8. Get a new vaccine against the new flu (score 4-5)	-	
Summary score items 1-7 (high) – Chronbach's alpha 0.7	50%	
Perceived self-efficacy* (scale 1-5; certainly not-certainly)		
1. Keep away from crowded places (score 4-5)	67%	
2. Practice better hygiene (score 4-5)	91%	
3. Avoid regions/persons[¥] with new flu (score 4-5)	89%	
4. Wear face mask (score 4-5)	71%	
5. Seek medical advice with the onset of flu symptoms (score 4-5)	91%	
6. Take antiviral medication (score 4-5)	80%	

	Survey 2 15-19 June (n = 478)	P-value† survey 1 vs. 2	Survey 3.1 follow-up‡ 11-20 August (n = 456)	P-value‡ survey 1 vs. 3.1	Survey 3.2 follow-up☏ 11-20 August (n = 478)	P-value‡ survey 2 vs. 3.2	Time trend 1-2	Time trend 2-3
	79%	ns	84%	<0.001	86%	<0.001	ns	+
	47%	ns	37%	<0.001	36%	<0.001	ns	–
	98%	ns	98%	ns	99%	ns	ns	ns
	97%	ns	99%	0.03	99%	ns	ns	ns
	90%	ns	95%	0.004	94%	0.01	ns	+
	81%	ns	90%	<0.001	87%	<0.001	ns	+
	56%	-	50%	-	60%	ns		ns
	92%	0.02	96%	<0.001	95%	0.05	+	+
	67%	<0.001	43%	<0.001	39%	<0.001	–	–
	61%	0.002	39%	<0.001	39%	<0.001	–	–
	49%	-	31%	-	27%	<0.001		–
	53%	<0.001	29%	<0.001	29%	<0.001	–	–
	22%	ns	26%	0.02	30%	0.003	ns	+
	5%	ns	15%	<0.001	15%	<0.001	ns	+
	6%	ns	9%	ns	12%	<0.001	ns	+
	16%	ns	29%	<0.001	31%	<0.001	ns	+
	19%	<0.001	16%	<0.001	14%	0.02	–	–
	8%	<0.001	6%	<0.001	4%	0.009	–	–
	9%	<0.001	12%	<0.001	15%	0.003	–	+
	40%	<0.001	39%	<0.001	36%	ns	–	ns
	47%	0.01	58%	ns	54%	0.01	–	+
	75%	ns	89%	<0.001	89%	<0.001	ns	+
	73%	0.001	74%	0.002	73%	ns	–	ns
	31%	ns	22%	<0.001	25%	0.009	ns	–
	72%	0.03	70%	<0.001	66%	0.03	–	–
	46%	0.005	40%	ns	39%	0.01	+	–
	21%	ns	33%	<0.001	31%	<0.001	ns	+
	54%	-	49%	-	53%	ns		ns
	38%	<0.001	50%	ns	50%	<0.001	–	+
	61%	ns	56%	<0.001	50%	<0.001	ns	–
	88%	ns	89%	ns	88%	ns	ns	ns
	78%	<0.001	64%	<0.001	66%	<0.001	–	–
	60%	<0.001	50%	<0.001	47%	<0.001	–	–
	87%	0.05	87%	0.02	86%	ns	–	ns
	80%	ns	71%	0.001	70%	<0.001	ns	–

Table 2 Trends over time in risk perception, anxiety and behavioural responses *(continued)*

	Survey 1 30 April-4 May (n = 456)	
7. Stay home from school or work (score 4-5)	56%	
8. Get a new vaccine against the new flu (score 4-5)	-	
Summary score items 1-7 (high) – Chronbach's alpha 0.9	55%	
Intention* (scale 1-5; certainly not-certainly)		
1. Keep away from crowded places (score 4-5)	76%	
2. Practice better hygiene (score 4-5)	93%	
3. Avoid regions/persons¥ with new flu (score 4-5)	89%	
4. Wear face mask (score 4-5)	70%	
5. Seek medical advice with the onset of flu symptoms (score 4-5)	91%	
6. Take antiviral medication (score 4-5)	82%	
7. Stay home from school or work (score 4-5)	61%	
8. Get a new vaccine against the new flu§ (score 4-5)	-	
Summary score items 1-7 (high) – Chronbach's alpha 0.9	60%	
Maladaptive response (scale 1-5; totally disagree-totally agree)		
The threat is exaggerated by media and government (score 4-5)	-	
It will not be as bad as predicted (score 4-5)	-	
Summary score - underestimation statements (high) – Chronbach's alpha 0.6	-	
There is nothing we can do about it (score 4-5)	-	
We will all be completely powerless (score 4-5)	-	
We will just have to accept it (score 4-5)	-	
Summary score - fatalism statements (high) – Chronbach's alpha 0.6	-	
I will move to a place without influenza (score 4-5)	-	
I will stock up and stay indoors (score 4-5)	-	
Summary score - avoidance statements (high) – Chronbach's alpha 0.7	-	
Information (scale 1-5)		
Amount of information received (score 4-5, much-very much)	52%	
Attention paid to information received (score 4-5, much-very much)	30%	
Is information of the government reliable? (score 4-5, reliable-very reliable)	62%	
Is information of the government sufficient? (score 4-5, sufficient-very sufficient)	58%	
Measures taken		
Practiced better hygiene	8%	
Avoided persons with influenza-like symptoms	-	
Avoided crowded places	3%	
Cancelled or did not book a holiday to areas with the new flu	0.2%	
Bought face mask	0.4%	
Bought antiviral medication	0.2%	
Something else	1%	
Summary score (any measures taken)	11%	

vs = versus;
† p-value obtained using Chi² tests;
‡ p-value obtained using McNemar tests;
ᵀ follow-up of survey 1;
ϖ follow-up of survey 2;
'-' data not collected in survey 1;
'+' indicates a significant increase over time;
'–' indicates a significant decrease over time;
ns = not statistically significant.

	Survey 2 15-19 June (n = 478)	P-value† survey 1 vs. 2	Survey 3.1 follow-up¥ 11-20 August (n = 456)	P-value‡ survey 1 vs. 3.1	Survey 3.2 follow-up☞ 11-20 August (n = 478)	P-value‡ survey 2 vs. 3.2	Time trend 1-2	Time trend 2-3
	50%	ns	52%	ns	50%	ns	ns	ns
	79%	-	69%	-	70%	‹0.001		–
	43%	‹0.001	38%	‹0.001	35%	0.001	–	–
	66%	0.001	62%	‹0.001	59%	0.001	–	–
	89%	ns	91%	ns	89%	ns	ns	ns
	81%	0.001	71%	‹0.001	72%	‹0.001	–	–
	57%	‹0.001	46%	‹0.001	44%	‹0.001	–	–
	89%	ns	84%	‹0.001	84%	0.01	ns	–
	76%	0.02	66%	‹0.001	65%	‹0.001	–	–
	53%	0.01	56%	ns	50%	ns	–	ns
	77%	-	67%	-	63%	0.001		–
	48%	‹0.001	41%	‹0.001	41%	0.006	–	–
	35%	-	56%	-	58%	‹0.001		+
	28%	-	49%	-	49%	‹0.001		+
	20%	-	40%	-	42%	‹0.001		+
	5%	-	14%	-	16%	‹0.001		+
	7%	-	14%	-	14%	‹0.001		+
	24%	-	43%	-	47%	‹0.001		+
	26%	-	48%	-	44%	‹0.001		+
	2%	-	1%	-	0%	0.04		–
	3%	-	2%	-	4%	ns		ns
	52%	-	39%	-	38%	‹0.001		–
	37%	‹0.001	53%	ns	48%	‹0.001	–	+
	21%	0.002	21%	‹0.001	23%	ns	–	ns
	53%	0.004	48%	‹0.001	45%	0.002	–	–
	42%	‹0.001	52%	0.02	47%	ns	–	ns
	12%	ns	36%	‹0.001	36%	‹0.001	ns	+
	4%	-	10%	-	9%	‹0.001		+
	3%	ns	7%	0.003	8%	‹0.001	ns	+
	0.4%	ns	0.9%	ns	1%	ns	ns	ns
	1%	ns	0.7%	ns	2%	ns	ns	ns
	0.4%	ns	0.4%	ns	2%	ns	ns	ns
	2%	ns	2%	ns	1%	ns	ns	ns
	14%	ns	40%	‹0.001	38%	‹0.001	ns	+

¥ *In the third survey 'avoiding regions with Influenza A (H1N1)' was changed into 'avoiding persons with influenza like symptoms'.*

* *Respondents were asked to imagine that governmental health institutes would recommend the preventive behaviour.*

§ *A vaccine against Influenza A (H1N1) became available in the Netherlands in November 2009.*

reported most often, by 36% of the respondents at the last survey. For the specific measures, a significant increase over time was observed for practicing better hygiene (12% in June, 36% in August), avoiding persons with influenza like symptoms (4% in June, 9% in August), and avoiding crowded places (3% in June, 8% in August) *(Table 2)*.

Factors associated with taking preventive measures and strong intention to comply (survey 3)
Univariate and multivariate logistic regression analyses were performed to identify factors significantly associated with: 1) taking one or more preventive measures and 2) strong intention to comply with government-advised preventive measures in the future *(Table 3)*. In this regression analysis variables of the survey in August (survey 3) were included.

Factors univariately associated with taking preventive measures but not significant in the multivariate analysis were: perceived severity, vulnerability, and efficacy of measures; underestimation and fatalism statements; amount of information received, and reliability of governmental information. From multivariate logistic regression analysis, predictors of taking preventive measures were no children in the household (OR 1.45; 95% CI 1.04-2.0), high anxiety (OR 1.93; 95% CI 1.43-2.61), higher level of self-efficacy (OR 1.68; 95% CI 1.26-2.22), more in agreement with statements on avoidance (OR 1.43; 95% CI 1.07-1.90), and paying much attention to the information on Influenza A (H1N1) (OR 2.36; 95% CI 1.67-3.33).

We also took a strong intention to comply with measures in the near future, when advised by the government, as an outcome (dependent) variable in the logistic regression analyses. Factors that were univariately associated but not significant in the multivariate analysis were: gender, level of education, employment status, marital status, perceived vulnerability, underestimation, fatalism, and avoidance statements, and attention paid to the information on Influenza A (H1N1). In the multivariate logistic regression model, predictors of a strong intention to comply were older age (>50 yrs: OR 2.61; 95% CI 1.39-4.90), higher levels of perceived severity (OR 1.62; 95% 1.07-2.44), feelings of anxiety (OR 2.22; 95% CI 1.44-3.42), believe in the efficacy of measures (OR 2.57; 95% CI 1.77-3.74) and self-efficacy (OR 21.53; 95% CI 14.70-31.55), and finding government information to be reliable (OR 1.74; 95% CI 1.19-2.55).

Discussion

In this population-based study performed in the Netherlands, we found that the level of knowledge regarding Influenza A (H1N1) increased between May and August 2009. At the same time, perceived severity of the new flu, perceived self-efficacy, and intention to comply with preventive measures decreased. The perceived reliability of information from the government also decreased from May to August. Feelings of anxiety decreased from May to June, and remained stable afterwards. From June to August 2009, perceived vulnerability increased and more respondents took preventive measures. Factors associated with taking preventive measures included no children in the household, high anxiety, high self-efficacy, agreeing with avoidance statements, and paying much attention to media information regarding Influenza A (H1N1). Having a strong intention to comply with government-advised preventive measures in the future was associated with

older age, high perceived severity, high anxiety, high perceived efficacy of measures, high self-efficacy, and finding governmental information to be reliable.

A clear strength of this study is that data collection took place during the 2009 Influenza A (H1N1) pandemic, in contrast to other studies performed at times when pandemic influenza was not regarded as a high threat and scenarios were based on hypothetical situations [12-19]. Another strength is that this study consists of three repeated survey rounds, enabling analysis of trends over time. This is in contrast to other recent studies, which consisted of a single cross-sectional survey [20-22]. Moreover, we followed-up individuals, guaranteeing that differences between survey rounds were not due to differences between study populations, but represent real trends over time [35]. Finally, we used an online questionnaire, which creates less social desirability bias than personal telephone interviews. The use of an Internet panel led to high response rates: 59%, 63%, and 79% in survey 1, survey 2, and survey 3, respectively.

Our study also has several limitations. First, the Internet panel members who responded to our online questionnaire were not fully representative of the general Dutch population. In our study, participants were more likely to be in the older age group (› 50 years) (52% versus 44%), of Dutch ethnicity (92% versus 80%), and unemployed/retired (43% versus 24%). We cross-tabulated all the measured constructs by age group (18-49 years/›50 years), employment status (employed/unemployed) and ethnicity (Dutch/non-Dutch) (data not shown). For these constructs, there were no differences between the Dutch and non-Dutch participants. Among both the older and unemployed the perceived efficacy, self-efficacy and intention to comply with measures were significantly higher, and they more agreed with statements on avoidance. Perceived vulnerability and reliability of governmental information were lower among both the older and unemployed. Furthermore, the older age group paid more attention to the information of the government. Among the unemployed the perceived severity was higher and they less agreed with the underestimation statements. This population difference may have led to a substantial bias in the absolute outcomes of *Table 2*, but only to a small bias in the trends over time or in the predictors of behavioural responses. Second, in the logistic regression analyses we may have lost some power, because we used dichotomized summary scales as predictors. However, we have performed additional regression analyses with the predictors as continuous variables, and found minimal differences (data not shown). Third, the validity of the questionnaire used in this study was not tested through a test-retest design, because the Influenza pandemic was ongoing and thus perceptions were not stable over time. Fourth, no data were obtained from non-responders.

This is the first national study to evaluate perceived risk, feelings of anxiety, and behavioural responses regarding Influenza A (H1N1) among the general public in the Netherlands. There was a decrease over time in perceived severity, anxiety and intention to comply with preventive measures. Initially, representatives of (inter)national health institutes predicted a worse-case scenario with large numbers of fatal cases, based on influenza pandemics in the past and early reports concerning the new Influenza virus [36]. In the following months, media attention decreased considerably, local viral transmission remained relatively limited in the Netherlands, and the Dutch government

Table 3 Predictors of taking preventive measures and strong intention to comply with measures regarding Influenza A (H1N1)

	Taking one or more preventive measures						
	Row %	OR_u	95% CI	p-value	OR_m	95% CI	p-value
Demographic characteristics							
Sex							
male	36.9	1.00					
female	41.5	1.21	0.93-1.58	0.1	-	-	-
Age							
18-29 years	35.1	1.00		ns	-	-	-
30-49 years	36.2	1.05	0.67-1.64				
above 50 years	42.0	1.34	0.88-2.05				
Ethnicity							
Dutch	39.1	1.00		ns	-	-	-
non-Dutch	39.0	1.00	0.62-1.60				
Education							
low	37.8	1.00		ns	-	-	-
intermediate	40.2	1.11	0.82-1.50				
high	39.3	1.07	0.76-1.49				
Employment status							
employed	38.9	1.00		ns	-	-	-
unemployed/retired	39.4	1.02	0.78-1.33				
Marital status							
single	39.4	1.00		ns	-	-	-
married/cohabited	39.3	0.99	0.71-1.39				
divorced/widowed	36.2	0.87	0.49-1.55				
Children < 18 yrs in household							
yes	34.0	1.00			1.00		
no	40.9	1.35	0.99-1.82	0.06	1.45	1.04-2.00	0.03
Knowledge score							
<4	36.5	1.00					
≥4	41.1	1.22	0.93-1.59	0.1	-	-	-
Perceived severity (sum. score)							
low severity	34.0	1.00					
high severity	44.5	1.56	1.20-2.03	0.001	-	-	-
Perceived vulnerability (sum. score)							
low vulnerability	35.4	1.00					
high vulnerability	47.5	1.66	1.25-2.20	<0.001	-	-	-
Anxiety (sum. score)							
low anxiety	30.6	1.00			1.00		
high anxiety	53.1	2.57	1.96-3.38	<0.001	1.93	1.43-2.61	<0.001
Perceived efficacy (sum. score)							
low efficacy	32.8	1.00					
high efficacy	46.4	1.77	1.36-2.31	<0.001	-	-	-
Perceived self-efficacy (sum. score)							
low self-efficacy	31.3	1.00			1.00		

	Strong intention to comply with government-advised preventive measures in the future†						
	Row %	OR_u	95% CI	p-value	OR_m	95% CI	p-value
	45.3	1.00					
	53.0	1.36	1.05-1.76	0.02	-	-	-
	28.9	1.00		‹0.001	1.00		0.007
	44.2	1.95	1.23-3.08		1.77	0.94-3.35	
	57.1	3.27	2.10-5.10		2.61	1.39-4.90	
	49.4	1.00		ns	-	-	-
	45.5	0.86	0.54-1.37				
	56.3	1.00		0.002	-	-	-
	45.9	0.66	0.49-0.89				
	42.6	0.58	0.42-0.80				
	41.5	1.00					
	58.9	2.02	1.55-2.63	‹0.001	-	-	-
	41.7	1.00		0.04			
	50.1	1.40	1.01-1.96				
	58.0	1.93	1.10-3.39		-	-	-
	44.8	1.00					
	50.6	1.27	0.94-1.69	0.1	-	-	-
	47.0	1.00		ns	-	-	-
	50.6	1.15	0.89-1.49				
	37.3	1.00			1.00		
	61.7	2.71	2.08-3.53	‹0.001	1.62	1.07-2.44	0.02
	45.2	1.00					
	57.7	1.66	1.25-2.19	‹0.001	-	-	-
	39.5	1.00			1.00		
	64.8	2.81	2.14-3.70	‹0.001	2.22	1.44-3.42	‹0.001
	31.0	1.00			1.00		
	70.1	5.21	3.94-6.89	‹0.001	2.57	1.77-3.74	‹0.001
	18.4	1.00			1.00		

Table 3 Predictors of taking preventive measures and strong intention to comply with measures regarding Influenza A (H1N1) *(continued)*

	Taking one or more preventive measures						
	Row %	OR_u	95% CI	p-value	OR_m	95% CI	p-value
high self-efficacy	48.6	2.08	1.59-2.72	<0.001	1.68	1.26-2.22	<0.001
Maladaptive response (sum.score)							
Underestimation statements							
(fully) disagree/not disagree-agree (1-3)	43.0	1.00					
(fully) agree (4-5)	33.4	0.67	0.51-0.87	0.003	-	-	-
Fatalism statements							
(fully) disagree/not disagree-agree (1-3)	43.3	1.00					
(fully) agree (4-5)	34.1	0.68	0.52-0.89	0.004	-	-	-
Avoidance statements							
(fully) disagree/not disagree-agree (1-3)	34.6	1.00			1.00		
(fully) agree (4-5)	46.2	1.63	1.24-2.13	<0.001	1.43	1.07-1.90	0.02
Amount of information received							
nothing/little/some (1-3)	33.2	1.00					
much/very much (4-5)	44.8	1.64	1.25-2.13	<0.001	-	-	-
Attention paid to the information							
(very) little/some (1-3)	33.1	1.00			1.00		
much/very much (4-5)	61.3	3.19	2.31-4.40	<0.001	2.36	1.67-3.33	<0.001
Reliability of governmental information							
not (at all)/little reliable (1-3)	36.0	1.00					
(very) reliable (4-5)	42.7	1.33	1.02-1.73	0.04	-	-	-
Sufficiency of governmental information							
not (at all)/little sufficient (1-3)	36.8	1.00					
(very) sufficient (4-5)	41.5	1.22	0.94-1.59	0.1	-	-	-
R^2					0.14		

Data from survey 3 were used for the regression analyses (August 2009, n=934).

ORu: univariate odds ratio;

ORm: multivariate odds ratio;

ns: not statistically significant.

[†] Included preventive measures, i.e.

1) keep away from crowded places;

2) practice better hygiene;

3) avoid persons with ILI;

4) wear face mask;

5) seek medical advice with the onset of flu symptoms;

6) take antiviral medication;

7) stay home from school or work;

8) get a new vaccine against the new flu.

	Strong intention to comply with government-advised preventive measures in the future†						
	Row %	OR_u	95% CI	p-value	OR_m	95% CI	p-value
	86.3	27.9	19.5-39.8	<0.001	21.53	14.7-31.55	<0.001
	56.5	1.00					
	38.2	0.48	0.36-0.62	<0.001	-	-	-
	57.1	1.00					
	39.5	0.49	0.38-0.64	<0.001	-	-	-
	45.7	1.00					
	54.3	1.41	1.08-1.84	0.01	-	-	-
	46.2	1.00					
	51.8	1.25	0.97-1.62	0.09	-	-	-
	44.4	1.00					
	66.7	2.51	1.81-3.47	<0.001	-	-	-
	39.8	1.00			1.00		
	59.9	2.26	1.74-2.94	<0.001	1.74	1.19-2.55	0.004
	46.2	1.00					
	52.0	1.26	0.97-1.63	0.08	-	-	-
					0.60		

announced that the pandemic appeared to be mild [37,38]. Decreasing trends over time in perceived severity and anxiety are consistent with the reality: the clinical picture of influenza turned out to be mild in course of time. The decrease in perceived reliability of information from the government was not surprisingly; in the beginning the general public believed the pandemic would be severe as pronounced by the government, but this turned out to be mild. This decrease in perceived reliability of governmental information was not alarming and did not result in more feelings of anxiety or in a lower intention to comply with measures. The increase in perceived vulnerability and number of individuals taking preventive measures may be an effect of the increasing number of Influenza A (H1N1) infected cases, including the first fatal case in The Netherlands in August 2009. Previous studies showed a similar effect. For instance with the inclining phase of the SARS outbreak in 2003, the prevalence of wearing a face mask and adopting better hand hygiene increased dramatically when the number of SARS cases increased [39].

During the current study period, there was no official recommendation from the Dutch government to take preventive measures; the government was in the process of preparing a national information campaign called 'Fight the flu'. This campaign was launched at the end of August 2009, and included announcements on television and a leaflet which was sent to every home in the country providing information about what people can do to prevent themselves and others. So, at the moment of the third data collection period the government had not yet actively informed the general public about preventive measures. For this reason, respondents were not only asked about preventive measures they had taken, but also about their intention to comply with government-advised preventive measures in the near future. People who took preventive measures during this 'pre-phase' of governmental advice were very alert to media information and seemed to be practicing preventive measures based on emotions such as anxiety. This is in line with results of the study conducted by Jones et al. [20] concluding that affective variables, such as self-reported anxiety over the epidemic, mediate the likelihood that respondents engage in protective behaviour. Rubin et al. [21] also found a significant association between anxiety and carrying out recommended behaviours. Similarly, studies on outbreaks of SARS found that anxiety was associated with taking preventive measures [39,40]. To date, there are only few published studies assessing factors that might explain compliance with preventive behaviours in case of an Influenza pandemic. Comparison with these studies is difficult because of differences in phrasing of questionnaire items and methods of analysis. Barr et al. [14] collected baseline data about willingness to comply with vaccination, isolation, and wearing a face mask among Australians during a hypothetical influenza pandemic, and found a higher level of willingness to comply among people with higher levels of threat perception and among those of older age. This is in agreement with our findings, where intention to comply with measures was also associated with older age and high perceived severity.

This is one of the first studies conducted during the course of the Influenza pandemic. Additional studies on risk perception among the public are needed to further understand the field of preventive behaviour as related to control of infectious diseases. Furthermore, these studies need to address emotional aspects such as anxiety, uncertainty, or embarrassment that play a role in decision-making. Finally, research regarding the translation of results from the above-suggested studies into risk communication is of utmost importance.

Our study has several implications for health authorities and public health policy. In case of an emerging infectious disease, as Influenza A (H1N1), it is very difficult to predict the further course of the outbreak. It is important that health authorities present a range of scenarios, not only worst-case but also other, more positive, scenarios. In the beginning of an outbreak, there are many uncertainties about the infectiousness and case fatality rate of the disease. Health authorities should not only communicate with the public about 'what is known' (the certainties), but they should also communicate about 'what is not known' (the uncertainties). In course of the outbreak, when more information becomes available, public health authorities should update their messages to achieve effective risk communication. This is essential not only to instruct and motivate the public to take preventive measures, but also to build trust in public health authorities and prevent misconceptions. Besides rational arguments (such as perceived severity and efficacy

of measures), emotional aspects like anxiety play a role in decision-making concerning preventive behaviour. Health authorities should acknowledge these emotional aspects and take these arguments into account in their risk communication with the general public.

Conclusion

Decreasing trends over time in perceived severity and anxiety are consistent with the reality: the clinical picture of influenza turned out to be mild in course of time. Although (inter)national health authorities initially overestimated the case fatality rate, the public stayed calm and remained to have a relatively high intention to comply with preventive measures. During future outbreaks of infectious diseases it is important that health authorities present a range of scenarios, not only worst-case but also other, more positive, scenarios. Health authorities should not only communicate with the public about 'what is known' (the certainties), but they should also communicate about 'what is not known' (the uncertainties). In course of the outbreak, when more information becomes available, public health authorities should update their messages to instruct and motivate the public to take preventive measures, to build trust in public health authorities and prevent misconceptions.

Competing interests
The authors declare that they have no competing interest.

Authors' contributions
All authors contributed to the study design. MB, DB, and HV played a main role in the data collection process. Data analysis was performed by MB and HV with advice of PvE. MB, DB, OdZ, and HV wrote the first draft of the manuscript; GK, PvE, JvS, and JHR critiqued the manuscript and contributed to further drafts. HV is the guarantor. All authors read and approved the final manuscript.

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CHAPTER 3

Mexican flu: risk perception of the general public, preventive behaviour and trust in governmental information

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Abstract

Aim

To gain a better understanding of the risk perceived by the Dutch public during the course of the Mexican flu pandemic, of how many and which members of the public adopted preventive behaviour and of the extent to which the public trusted governmental information.

Methods

An online questionnaire, used for both cross-sectional studies (first two surveys) and follow-up studies (last two surveys). Between 10 and 17 November 2009, 754 participants completed an online questionnaire. Surveys were previously conducted in May 2009 (n=572), June 2009 (n=620) and August 2009 (n=934).

Results

In November, 2009, 38% of the respondents considered the Mexican flu a serious illness, and 36% felt they were susceptible to the disease. Feelings of anxiety diminished over the course of the pandemic. Of the respondents, 73% adopted preventive behaviour – mainly in relation to hygiene – to avoid contracting Mexican flu. This group consisted primarily of people who reported feeling anxious, thought that improving hygiene was an effective preventive measure, had closely followed media coverage of the flu, felt government information was reliable or did not live in households with children. Over half (58%) planned to be vaccinated against Mexican flu, if eligible. Of the remaining 315 respondents, 40% said they were afraid of serious side effects and 35% questioned the vaccine's efficacy, while 33% were not convinced the vaccine had been tested properly. Nearly half of the respondents had read the brochure, distributed door-to-door, called Fight the flu (in dutch 'Grip op griep'), and one-third had seen the TV adverts. The key sources of information deemed reliable by over half of the respondents were agencies of the national government, including the Ministry of Health, Welfare and Sport (VWS) and the National Institute for Public Health and the Environment (RIVM).

Conclusion

During the course of the Influenza A (H1N1) pandemic, perceived severity among the Dutch public continued to decline, while perceived susceptibility increased over time. The public's appraisal of the threat was clearly realistic. Three quarters of the public had adopted preventive behaviour against the illness, and over half were prepared to be vaccinated, if eligible. The potential for serious side effects and doubts about the vaccine's efficacy were the key reasons for declining vaccination. This objection ought to be addressed in the development of future education campaigns for vaccines.

Introduction

In April 2009, Mexico witnessed the outbreak of a new flu virus, quickly called the 'Mexican flu'. Since then, around 8,000 people in about 200 countries have died of the illness [1,2]. By mid-December, the Mexican flu and related complications had claimed 51 lives in the Netherlands. In August 2009, the Dutch government undertook a nationwide education campaign, called Grip op griep, involving the distribution of a brochure door-to-door and radio/TV adverts. Starting in November, high-risk individuals were offered the vaccination, of which three quarters were actually vaccinated [3,4].

Since the start of the pandemic, the Municipal Health Service (GGD) Rotterdam-Rijnmond and the RIVM have worked with Erasmus MC and Maastricht University to investigate the general public's response to media coverage of the Mexican flu, studying the extent to which people felt threatened or concerned, whether they adopted preventive behaviour and their perception of the education campaign. In June 2009, this journal published our short article, which discusses the public perception following the first confirmed cases of the Mexican flu on Dutch soil [5]. The present article continues to describe the public perception, and how it changed over the course of the pandemic. We present the results of the last survey conducted in November 2009, comparing them to the surveys conducted previously in May, June and August 2009. The article also describes determinants of practicing better hygiene and willingness to comply with vaccination.

Participants and methods

Surveys conducted during the flu pandemic

Four surveys were conducted during the pandemic. The first was done in May 2009 when the first cases in the Netherlands were announced, with the second following in June 2009 when the WHO declared its highest level of alert. The third survey followed in August 2009 when the first fatal case occurred in the Netherlands, after which a fourth survey was conducted from 10 November 2009 up to and including 17 November 2009, coinciding with the vaccination campaign.

Recruitment and questionnaire

The Flycatcher Internet panel (*www.flycatcher.eu*), an ISO-certified nationwide panel of some 20,000 Dutch citizens, was involved in each survey. The panel is representative of the Dutch population in terms of gender, age, educational level and province of residence. For the first and second surveys, independent samples were taken of some 1,000 panel members aged 18 and over. As a follow-up, the third and fourth surveys were conducted. The third involved only respondents who had participated in the first and second surveys, while the fourth only involved respondents who had participated in the third survey. Panel members received an email with a link to the questionnaire based on previous questionnaires about risk perception of SARS and avian flu and on the theoretical behavioural models, including the Protection Motivation Theory and the Health Belief Model [6-9]. Respondents could access and complete the questionnaire online for five to ten days, after which they received modest compensation.

Analysis
Results of the last survey conducted in November 2009 are compared with the surveys conducted previously in May, June and August 2009. For the fourth survey, conducted in November 2009, univariate and multivariate logistic regression analyses were performed to identify determinants of practicing better hygiene and willingness to comply with vaccination.

Results

Response rates and demographic variables
The questionnaire was completed in May and June by 572 and 620 respondents, respectively, of which 934 and 754 took part in the follow-up surveys in August and November 2009, respectively. Just as many women completed the questionnaire as men. The ages of the respondents participating in the November survey ranged from 18 to 29 (9%), 30 to 49 (35%) and 50 and over (56%). The educational levels of these respondents ranged from low (39%), intermediate (36%) and high (25%). The overwhelming majority (92%) were Dutch nationals, and 26% of the households included one or more children under the age of 18. The demographic variables remained virtually unchanged across all surveys.

Risk perception and feelings of worry
In November, 38% of the respondents said they considered Mexican flu a serious illness, a lower proportion compared to the previous surveys in May (80%), June (67%) and August (41%). The percentage of respondents who considered themselves susceptible to the illness continued to increase, however, reaching 36%, as compared to the proportion in May (18%), June (22%) and August (28%). Public concern about Mexican flu declined during the course of the pandemic, with 36% feeling concerned or very concerned in May compared to only 18% in November.

Adopting preventive behaviour
The percentage of respondents who reported adopting preventive behaviour against Mexican flu increased from 11% in May to 73% in November 2009. More frequent hand washing was most often reported (61%), followed by more frequent use of disposable tissues for coughing and sneezing (34%), avoidance of contact with flu sufferers (25%) and vaccination against Mexican flu (24%)). Respondents with no children (OR 1.7; 95%-CI 1.2-2.5), felt anxious about Mexican flu (OR 2.7;1.9-3.9), considered preventive hygiene behaviour effective (OR 6.2;4.1-9.2), intensively followed media coverage of the pandemic (OR 1.6;1.1-2.4) and trusted the government information on the illness (OR 1.5;1.0-2.1) were more likely to adopt preventive hygiene behaviour *(Table 1)*.

Willingness to become vaccinated
Over half (58%) of the respondents were willing to get vaccinated against Mexican flu, if eligible. Of the remaining 315 respondents, 40% were afraid of potentially serious side effects and 35% questioned the vaccine's efficacy, while 33% were not convinced the vaccine had been properly tested. Male respondents (OR 1.6; 1.0-2.4), those with a low level of education (OR 1.9; 1.1-3.3), unemployed (OR 1.6; 1.1-2.4), living in households

Table 1 Determinants of taking hygiene measures to prevent Mexican flu (n=754)*

Factor	% of respondents that took hygiene measures	Oddsratio (95%-CI)§	
		Univariate	Multivariate
Children <18 yrs in household			
yes	58.2	1.0	1.0
no	67.2	1.5 (1.1-2.1)	1.7 (1.2-2.5)
Level of anxiety			
low level of anxiety	53.8	1.0	1.0
high level of anxiety	78.1	3.1 (2.2-4.2)	2.7 (1.9-3.9)
Perceived efficacy hygiene measures			
certainly not / probably not / even	28.9	1.0	1.0
probably / certainly	74.5	7.2 (4.9-10.6)	6.2 (4.1-9.2)
Attention paid to information			
nothing / little / some	58.7	1.0	1.0
much / very much	77.2	2.4 (1.7-3.4)	1.6 (1.1-2.4)
Reliability of information of the government			
(very) unreliable / not (un)reliable	58.0	1.0	1.0
(very) reliable	71.3	1.8 (1.3-2.4)	1.5 (1.0-2.1)

§ *95%-CI 95% confidence interval;*

* *the following determinants are not included in this table, because they were not significant in the multivariate model (although they were univariate a significant determinant of taking hygiene measures); gender, perceived severity of Mexican flu, perceived vulnerability to Mexican flu, amount of information received, amount of information of the government. The following determinants were univariate not a significant determinant of taking hygiene measures: age, ethnicity, education, employment status, marital status, knowledge about Mexican flu.*

without children (OR 1.6; 1.0-2.5), who perceived the flu as a serious illness (OR 2.2; 1.4-3.4), felt anxious about the flu (OR 2.0; 1.3-3.0), were convinced of the vaccine's efficacy (OR 11.9; 7.9-17.7) and trusted the government information (OR 3.2;2.1-4.7) were identified as the groups most willing to be vaccinated *(Table 2)*.

Government education campaign

Most respondents (92%) had received a great amount of information about the Mexican flu: nearly half had read the *Grip op griep* brochure, distributed door-to-door, and 35% had seen the TV adverts. One third said they adopted more preventive behaviours after receiving the government information.

Agencies of the national government, including the Ministry of Health, Welfare and Sport (VWS) and the National Institute for Public Health and the Environment (RIVM), proved key sources of information, followed by infectious disease experts (such as virologists), family and friends. Most respondents trusted the information provided by their own general practitioner or GGD (73% and 62%, respectively) and over half trusted the information issued by the RIVM and VWS (57% and 56%, respectively). Thirty-five percent took the initiative to find information about the Mexican flu on their own in search of additional details about the symptoms, vaccine and treatment.

Table 2 Determinants of willingness to get vaccinated against Mexican flu (n=754)*

	% of respondents with willingness to get vaccinated	Oddsratio (95%-CI)§	
		Univariate	Multivariate
Gender			
female	55.5	1.0	1.0
male	60.8	1.3 (0.9-1.7)	1.6 (1.0-2.4)
Education			
high	55.0	1.0	1.0
intermediate	53.7	1.0 (0.7-1.4)	1.0 (0.6-1.6)
low	64.5	1.5 (1.0-2.2)	1.9 (1.1-3.3)
Employment status			
fulltime/parttime	50.6	1.0	1.0
unemployed	68.1	2.1 (1.5-2.8)	1.6 (1.1-2.4)
Children <18 yrs in household			
yes	49.0	1.0	1.0
no	61.5	1.7 (1.2-2.5)	1.6 (1.0-2.5)
Perceived severity			
low severity	45.9	1.0	1.0
high severity	74.0	3.4 (2.5-4.6)	2.2 (1.4-3.4)
Level of anxiety			
low level of anxiety	48.4	1.0	1.0
high level of anxiety	70.0	2.5 (1.8-3.4)	2.0 (1.3-3.0)
Perceived efficacy vaccination			
certainly not / probably not / even	20.8	1.0	1.0
probably / certainly	79.0	14.3 (9.9-20.6)	11.9 (7.9-17.7)
Reliability of information of the government			
(very) unreliable / not (un)reliable	42.5	1.0	1.0
(very) reliable	73.1	3.7 (2.7-5.0)	3.2 (2.1-4.7)

§ *95%-CI 95% confidence interval;*

* *the following determinants are not included in this table, because they were not significant in the multivariate model (although they were univariate a significant determinant of high intention to get vaccinated); age, marital status, perceived vulnerability to Mexican flu, amount of information received, amount of attention paid to information on Mexican flu, amount of information of the government. The following determinants were univariate not significant determinant of high intention to get vaccinated: ethnicity, knowledge about Mexican flu.*

Conclusion

During the course of the pandemic, perceived severity and concern about the Mexican flu in the Netherlands decreased, while the perceived susceptibility increased. This demonstrates that the public's perception of the situation was realistic, as the flu was less severe than initially expected. Between May and November 2009, the public began adopting – in growing numbers – preventive behaviour. Moreover, half of the respondents indicated a willingness to be vaccinated, if eligible. The key reasons why individuals, if eligible, declined vaccination included the possibility of serious side effects and uncertainty about the vaccine's efficacy. These results are comparable to the results of an as-yet unpublished study into the human papillomavirus (HPV) vaccination campaign, which also demonstrated that uncertainty about the vaccine's safety and efficacy were key reasons why people opted to not be vaccinated (Qrius market research, 2009, data as yet unpublished). Future vaccination campaigns must address these aspects.

Believe in the efficacy of preventive measures was a main reason among the public for taking such measures. Other Dutch studies confirm this finding. Zijtregtop et al. (2009) conducted research into the willingness of the Dutch public to be vaccinated against pandemic influenza [10], concluding that among those least willing to be vaccinated, confidence in the vaccine's efficacy and perceived severity of the illness were both low. Van den Dool et al. (2008) studied the attitudes of hospital staff in relation to seasonal and other flu vaccines [11], concluding similarly that staff who are convinced of a vaccine's benefits are more likely to be willing to be vaccinated. Apparently, the willingness to adopt a preventive behaviour depends in part on more affective factors, such as anxiety about the flu pandemic, as also described in other studies [12,13].

Areas for improvement to reach more people with education

The findings of this study suggest several areas for improvement in risk communication for future infectious disease outbreaks. Nearly half of the respondents had read the brochure, distributed door-to-door, and one-third had seen the TV adverts. While the information did reach part of the public, it would be useful to assess how to reach the rest. For the public, the national government is the key source of information, and nearly half of the respondents considered it reliable. Accordingly, the government is advised to continue informing the public about the course – and decline – of an epidemic, with a view to making a realistic appraisal of the situation [14,15]. In addition to rational arguments, the information should address such affective factors as anxiety and concern. Moreover, the effectiveness and safety of the recommended preventive behaviour should also be explained.

Conflict of interest: none indicated

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CHAPTER 4

Pandemic influenza A (H1N1) vaccination in the Netherlands: Parental reasoning underlying child vaccination choices

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Abstract

Introduction
During the 2009 influenza A (H1N1) pandemic, parents in the Netherlands were recommended to vaccinate healthy children between six months and five years of age. The aim of this study was to examine reasons for (non-)acceptance, risk perception, feelings of doubt and regret, influence of the social network, and information-seeking behavior of parents who accepted or declined H1N1 vaccination.

Methods
Data on accepters were collected via exit interviews following the second-dose vaccination round in December 2009 (n=1227). Data on decliners were gathered in June and July 2010 with questionnaires (n=1900); 25 parents participated in in-depth interviews.

Results
The most reported reasons for parental acceptance of H1N1 vaccination were "I don't want my child to become sick" (43%), "Mexican flu can be severe" (10%), "the government advises it, so I do it" (6%), and "if I don't do it, I will regret it" (6%). The most reported reasons declining the vaccination were "fear of side effects/harmful consequences" (51%), "just having a bad feeling about it" (46%), and "the vaccine was not thoroughly tested" (39%). More decliners than accepters experienced feelings of doubt about the vaccination decision (decliners 63% versus accepters 51%, $p<0.001$), and decliners reported more often information-seeking behavior (decliners 76% versus accepters 56%, $p<0.001$). Decliners more frequently solicited advice from their social network than accepters (decliners 72% versus accepters 61%, $p<0.001$). Furthermore, accepters more often reported social influence on their vaccination decision (accepters 58% versus decliners 38%, $p<0.001$) and experienced more negative feelings after their vaccination decision (accepters 8% versus decliners 2%, $p<0.001$). Immigrant accepters and decliners more often had feelings of doubt and regret about the vaccination decision, solicited advice more often from their social network, and were more often influenced by this advice compared to native Dutch parents.

Conclusion
To optimize response rates in future vaccination campaigns, health authorities should provide more information on vaccine benefits and risks, tailoring this information to specific risk groups. Health authorities should also invest in the development and implementation of effective vaccine risk/benefit communication tools.

Keywords
Influenza A (H1N1) vaccination, parental reasoning, vaccination choices, feelings of doubt, social influence, information-seeking behavior.

Introduction

In April 2009, an outbreak of a novel influenza strain occurred in Mexico and the United States, spreading rapidly to other countries. Influenza A (H1N1), also known as "swine flu" or "Mexican flu", became one of the most widespread pandemics [1]. Although many individuals and countries conceptualized it as "mild" in severity, the overall burden of illness was considerable [2]. In the Netherlands, H1N1 led to 2193 hospitalizations and 63 deaths among nearly 17 million inhabitants [3]. In the early phase of the pandemic, control measures included patient isolation, quarantine of contacts, and antiviral therapy. In June 2009, when the World Health Organization raised the pandemic alert to phase 6, the focus in the Netherlands shifted towards delaying viral spread through population-based measures such as hand and respiratory hygiene [4-6]. The vaccine against H1N1 became available in November 2009.

The Dutch government ordered 34 million vaccines in order to vaccinate the entire Dutch population with two doses, if necessary. The Dutch Health Council advised the Minister of Health and Welfare about the vaccination strategy to be followed; vaccination was recommended for the same target groups as the seasonal influenza vaccination, including individuals at medical risk, health care workers, pregnant women with underlying medical conditions, and all persons aged 60 years and older [7]. Additionally, the Dutch Health Council advised vaccination for all (healthy) pregnant women [8]. These target groups were vaccinated by general practitioners, and two vaccine doses were recommended. During the course of the pandemic, relatively large numbers of children younger than five years were admitted to the hospital and intensive care units. Young children had a higher risk of complications such as pneumonia and severe secondary bacterial infections, most likely because their immune systems remain immature and these children have had no previous contact with these viruses [9,10]. As a result, in November 2009 the Dutch Health Council also recommended vaccination for all children aged six months to five years [11].

In order to rapidly vaccinate all 800,000 children aged six months to five years in the Netherlands, a national mass vaccination campaign was launched and coordinated by the Municipal Public Health Services. Vaccination was carried out in sports and congress centres. The vaccinations were offered free of charge in two rounds; the first round was held at the end of November 2009 and the second in mid-December 2009. In most European countries, H1N1 vaccination uptake among children was low with 5% in Italy (children above 6 months attending day-care centres), 8% in Germany (children under 14 years) and 20% in England (children under 5 years) [12-14]. In the United States, H1N1 vaccination uptake among children aged 6 months to 5 years was 33% [15]. Although response rates in the Netherlands were higher than most other countries (first round 71%, second round 59%), a substantial number of parents decided to not have their child vaccinated against H1N1 [16,17]. In the Netherlands, vaccinations within the routine National Immunisation Programme (NIP) are also offered free of charge and on a voluntary basis. Vaccination against 11 different infectious diseases are included in the programme and are given to children aged 2, 3, 4, 11, 14 months and 4, 9, 12 years. Vaccination uptake is considerably high; above 90% for all vaccinations included in the NIP in 2010 [18]. Surveillance of perceptions and behavioral responses during

infectious disease outbreaks provides useful information for health risk communication and strategies for instructing and motivating the public to take preventive measures, but also is useful in building trust of public health authorities and preventing misconceptions [19,20]. Several studies were performed focusing on the vaccination intention of the general public in 2009 [21-25], before national vaccination campaigns were launched, and investigated the intention to vaccinate, which is often more positive than actual vaccination behavior [26,27]. A number of studies investigated actual H1N1 vaccination behavior [12-14, 28-32]. Most studies focused on the general public or on specific risk-groups other than parents of healthy children, and most described either the accepters or the decliners of H1N1 vaccination, but not both groups. Our study aimed to examine reasons for (non-)acceptance, risk perception, feelings of doubt and regret, social influence, and information-seeking behavior of parents in the Netherlands who accepted or declined H1N1 vaccination for their healthy child.

Material and methods

Participants

This study was conducted among parents of healthy children aged six months to five years (born after 23 November 2004 and before 23 May 2009). A sample size of 3000 parents was determined by feasibility and costs, and we aimed to include minimal 1000 parents who accepted and 1000 parents who declined H1N1 vaccination for their child. Two-dose vaccine was recommended with a time interval of 3 weeks between the two dosages. The first round was held from 23 to 28 November; the second round was held from 14 to 18 December 2009. Children who missed their first vaccination in November, had the opportunity to catch-up this vaccination in December 2009, and to receive their second vaccination in January 2010 at a Youth Health Center. Data on parents who accepted H1N1 vaccination were collected during the second round at 15 and 17 December 2009. Parents were approached for exit interviews by trained interviewers at two sports and congress centres in the southwestern region of the Netherlands (Vlaardingen and Rotterdam). For data collection among decliners, a sample of families was randomly selected from a database of children living in Rotterdam and the surrounding municipalities, who were registered as unvaccinated against H1N1. It took several months for the Dutch authorities to finalize this database, therefore data on parents who declined H1N1 vaccination were gathered mid 2010 (between 18 June and 27 July). A total of 10,053 parents received an introductory letter by mail, a two-page questionnaire, and a prepaid return envelope. The letter articulated the study objectives: to obtain more insight into the reasons why parents decided not to vaccinate their child and to provide useful information for future vaccination campaigns. The letter indicated that they received the questionnaire because their child was registered as having not been vaccinated against H1N1. Parents could fill out their telephone number at the end of the questionnaire to be selected for an in-depth interview.

Questionnaires

Based on existing questionnaires for risk perception and precautionary behaviors of the general public during the 2009 H1N1 pandemic and during the SARS and avian influenza outbreaks [22,33,34], two questionnaires were developed (one for accepters

and one for decliners) with over half of the questions formulated exactly the same. These questionnaires were based on an integrated model to explain health behavior, including constructs from the Protection Motivation Theory [35] and the Health Belief Model [36]. Questions were aimed at demographic characteristics, reasons for accepting/declining H1N1 vaccination, risk perception, feelings of doubt and regret, social influence, and information-seeking behavior.

In-depth interviews

In-depth interviews were held to obtain more detailed information about the reasons for disregarding governmental vaccination advice. Reasons for declining vaccination were clustered into nine categories in the questionnaire. In-depth interviews were held with 25 parents who expressed the following reasons: fear of side effects/harmful consequences (category 1); just having a bad feeling about it (category 2); vaccine was not thoroughly tested (category 3); no trust in effectiveness of the vaccine (category 4); contradictory messages in the media (category 5); no need to have my child vaccinated against a mild flu (category 6); no trust in the government (category 7); my child is never sick (category 8); and principle convictions (religion) or belief in alternative medicine (homeopathy, anthroposophy) (category 9). The in-depth interviews were semi-structured to enable participants to talk in more detail about their decision to not have their child vaccinated. Pre-planned questions were asked, and open-ended questions were formulated on the basis of participant responses.

Statistical methods

SPSS for Windows Release 17.0 (SPSS Inc., Chicago, IL, USA) was used for analyses of the quantitative data from the exit interviews of accepters and the survey of decliners. The Chi-squared test was used to test statistical significance of group differences (gender, age, educational level, and ethnicity) and of differences between accepters and decliners regarding feelings of doubt and regret, social influence, and information-seeking behavior. Additionally, due to significant differences in demographic characteristics between the accepters and decliners, we performed logistic regression to adjust for differences in gender, age, education, and ethnicity between accepters and decliners. A p-value less than 0.05 was considered statistically significant.

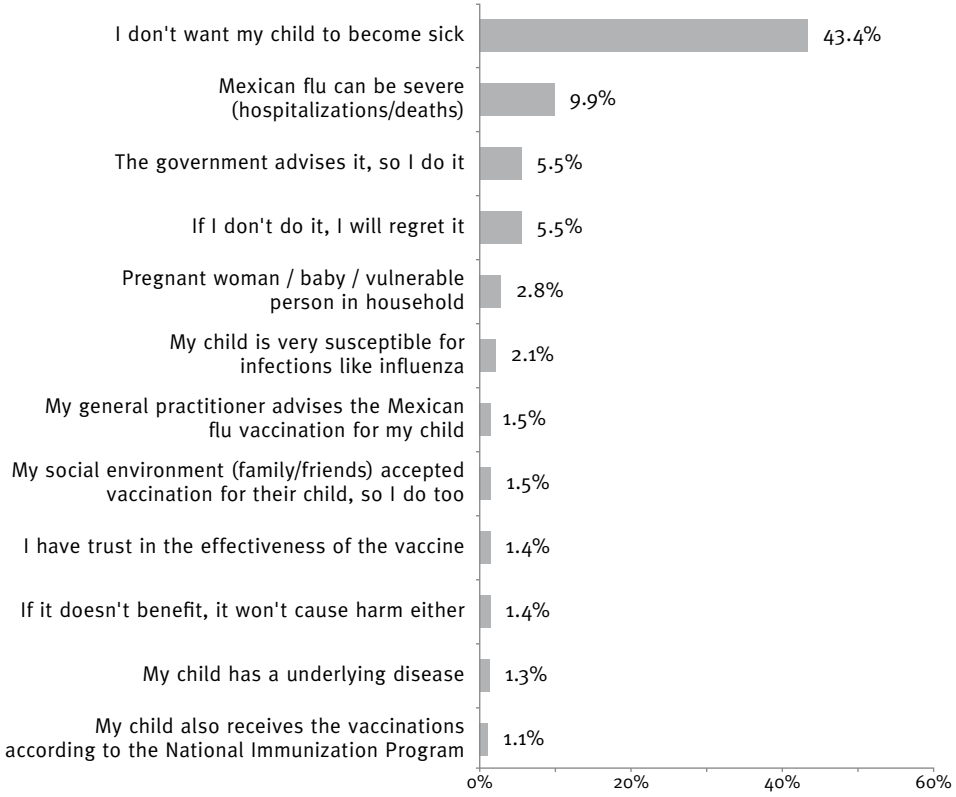
Results

Demographic characteristics

A total of 1227 parents who accepted the H1N1 vaccination for their child participated in exit interviews during the mass vaccination campaign in December 2009. Of these accepters, 76% was female. Their age varied from 30 years or younger (35%), 31-40 years (54%), and older than 40 years (11%). Twenty-nine percent had a lower education (i.e. primary education, lower general or lower vocational education or less), 37% an intermediate (i.e. secondary general or vocational education), and 35% a higher educational level (i.e. higher professional education or university). Nearly 40% were immigrants, including 22% first-generation immigrants (born abroad) and 17% second-generation immigrants (had at least one immigrant parent).

We sent the questionnaire to 10,053 parents who declined H1N1 vaccination. Of these decliners, 1900 responded (19%), of which the majority (81%) was female. Age varied from 30 years or younger (25%), between 31 and 40 years (60%), and older than 40

Figure 1 Parental reasons for accepting Influenza A (H1N1) vaccination for their child (n=1227)



Note that only one reason could be given;

n=73 (5.9%) of the accepters reported another reason;

of n=207 (16.9%) reason was missing.

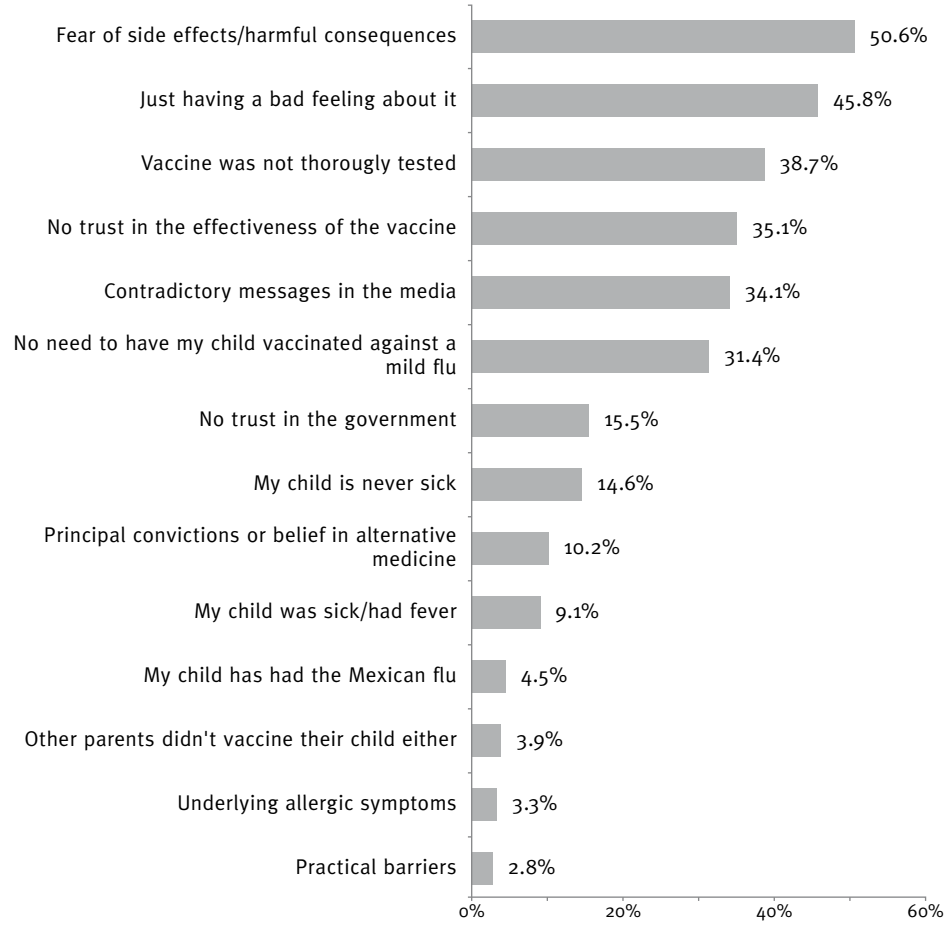
years (15%). Twenty-three percent had a lower, 32% an intermediate, and 45% a higher educational level. One-third of the decliners were immigrants, including 18% first-generation and 13% second-generation immigrants.

There were significant differences in the distribution of demographic characteristics between the accepters and decliners; there were more females, more parents aged 31-40 years, more parents with a higher educational level, and more native Dutch parents among the decliners.

Decision-making of accepters

Figure 1 shows the single main reason for parents to accept H1N1 vaccination for their child. The most reported reasons for acceptance were "I don't want my child to become sick" (43%), "Mexican flu can be severe" (10%), "the government advises it, so I do it" (6%), and "if I don't do it, I will regret it" (6%).

Figure 2 Parental reasons for declining Influenza A (H1N1) vaccination for their child (n=1900)



Note that more than one reason could be given (therefore the distribution of answers is not comparable to figure 1).

Table 1 Feelings of doubt and regret, social influence, and information-seeking behavior of parents who accepted H1N1 vaccination, by demographic characteristics (n=1227)

	Gender			Age		
	Male	Female	P-value	≤ 30 yrs	› 30 yrs	P-value
1. Feelings of doubt and regret						
Did you have doubts about vaccinating your child against Mexican flu?						
Some / many doubts	45%	53%	0.03	53%	50%	ns
What are dominant feelings now that your child has been vaccinated?						
Predominantly negative feelings (i.e. fear, doubt, restlessness, panic)	6%	9%	ns	8%	9%	ns
2. Social influence						
Did you ask advice from other people about vaccinating your child?						
Yes	54%	63%	0.005	64%	60%	ns
If yes; Was this advice of influence on your decision to vaccinate your child?						
Probably / certainly	58%	58%	ns	64%	54%	0.006
3. Information-seeking behavior						
Have you actively sought information about Mexican flu vaccination?						
Yes	59%	54%	ns	55%	56%	ns
If yes; How many hours did you spent on searching information?						
›2 hours	19%	27%	0.05	25%	25%	ns
If yes; Did you find the information you sought?						
Yes, largely	77%	78%	ns	78%	78%	ns
Did you visit internet sites critical of vaccination?						
Yes	23%	22%	ns	20%	24%	ns

[†] *lower educational level (i.e. primary education, lower general/vocational education or less);*

[‡] *intermediate educational level (i.e. secondary general or vocational education);*

[₮] *higher educational level (i.e. higher professional education or university);*

ns = not significant. P-values were derived by Chi-squared tests.

Table 1 shows feelings of doubt and regret, social influence, and information-seeking behavior of accepters, according to demographic characteristics. Fifty-one percent experienced feelings of doubt about the decision to vaccinate their child, mostly related to fear of side effects/harmful consequences (46%), contradictory messages in the media (22%), vaccine effectiveness (12%), and H1N1 severity (9%; data not shown). Female and immigrant accepters were more likely to experience feelings of doubt. After vaccination, 8% had predominantly negative feelings (i.e. fear, doubt, restlessness, panic); immigrant accepters were more likely to experience these negative feelings than native Dutch accepters.

The majority of accepters (61%) solicited advice from their social network about vaccinating their child. The most reported sources for advice were friends (44%), family (43%), and/or general practitioners (42%; data not shown). Female and immigrant accepters were more likely to ask advice from their social network. More than half of

	Educational level				Ethnicity			Overall	
	Lower†	Intermediate‡	Higher¥	P-value	Native Dutch	Immigrant	P-value	%	n/ntot
	49%	53%	51%	ns	48%	58%	0.002	51%	(623/1224)
	9%	9%	6%	ns	7%	12%	0.007	8%	(88/1082)
	56%	64%	61%	ns	59%	66%	0.04	61%	(743/1217)
	61%	55%	58%	ns	52%	61%	0.03	58%	(419/726)
	50%	54%	61%	0.007	53%	61%	0.006	56%	(679/1223)
	25%	25%	26%	ns	21%	30%	0.02	25%	(168/668)
	79%	77%	79%	ns	81%	73%	0.04	78%	(515/663)
	18%	21%	26%	0.04	21%	23%	ns	22%	(206/920)

the parents (58%) who asked advice from their social network reported that this advice influenced their vaccination decision. Younger parents (≤ 30 years) and immigrants were more likely to report social influence on their vaccination decision.

Fifty-six percent of accepters had actively sought information about H1N1 vaccination. Parents with a higher educational level and immigrants more often sought information. The majority of the respondents who sought information (75%) spent 2 h or less on searching information about H1N1 vaccination. Female and immigrant accepters spent more hours on searching information. Of the information-seeking respondents, 78% largely found the information they sought; immigrants less often found the information they were seeking. Twenty-two percent of accepters visited Internet sites that were critical of vaccination; higher educated accepters visited these Internet sites more often compared to those lower educated.

Decision-making of decliners

Figure 2 illustrates parental reasons for declining H1N1 vaccination for their child. Please note that more than one reason could be given, therefore the distribution of answers is not comparable to *figure 1*. The most reported reasons for declining H1N1 vaccination were

Table 2 Illustrative quotes from in-depth interviews of parents who declined H1N1 vaccination

Quote number	Selected quotes
1. Fear of side effects/harmful consequences	
Q1	*"I was searching information on the Internet about the vaccine. I read that it contains mercury. I thought: No, I will not give this to my child! I know mercury from the thermometers and I know how dangerous that is. I am a layperson, so when I hear that the vaccine contains mercury, I immediately think no!"*
Q2	*"The vaccines were produced in a short period in great numbers; to make this possible all kinds of adjuvant were added. I found that harmful, so I refused to give that to my child. It was unknown if these adjuvant could have negative consequences for my child."*
Q3	*"In a Dutch newspaper I read that the effectiveness of the vaccine was not yet proven, and that the vaccine has possible consequences for the development of the brain. Well at that moment I totally thought: we aren't going to do this."*
2. Just having a bad feeling about it	
Q4	*"I'm a parent and I want to make a well-considered decision. If I don't trust it, I rather say no."*
Q5	*"I had doubts, one moment I thought I will do it, next moment I thought I will not do it. Well, and my children didn't get sick so I do not regret it."*
3. Vaccine was not thoroughly tested	
Q6	*"We were wondering whether the vaccine was well enough tested and what the side effects are, in particularly for the longer term. Well, and that is simply unknown and will become known in about ten years or something. In the past there were the DES mothers.*[1] *In first instance, there were no problems, but later on it became clear that it had negative effects for the children born from these mothers."*
4. No trust in the effectiveness of the vaccine	
Q7	*"I understood that the vaccination could not guarantee that you will not get the flu, so the effectiveness was also unknown."*
5. Contradictory messages in the media	
Q8	*"A number of experts gave contradictory information about the safety and effectiveness of the vaccine."*
Q9	*"To our opinion the Mexican flu was exaggerated by media, and the pharmaceutical industry was pushing parents to vaccinate their children."*
6. No need to have my child vaccinated against a mild flu	
Q10	*"I understood that the Mexican flu can be severe, but in general is mild, and that the risks of the disease are limited. It is a consideration of the vulnerability of my child for the disease and how severe it will be for him. But I just found the flu not severe enough."*
Q11	*"If my children would get the flu than they just had to stay in bed and get better, maybe for a week or something… I didn't have the idea at all that they could die because of this flu."*
7. No trust in the government	
Q12	*"To our opinion the Mexican flu was exaggerated by the media, and the pharmaceutical industry has taken great advantage of the whole vaccination campaign."*
Q13	*"I found it a bit hysterical. Every year, a number of people die because of seasonal influenza too."*

Quote number	Selected quotes
8. My child is never sick	
Q14	*"My child is never sick, actually very healthy. I have a lot of trust in my general practitioner. I asked her for advice. She said that this flu was comparable to the seasonal flu, not more severe, and that a healthy child will survive it. I didn't have the feeling that my child was very susceptible for it. He is not fragile."*
9. Principle convictions or belief in alternative medicine	
Q15	*"We already decided not to vaccinate our children before we received the invitation. Our children are not getting vaccinated at all. The reason is our religion. We are Calvinists. The Bible does not forbid us to vaccinate our children, but it is more that we trust God, God will protect us."*
Q16	*"We are very critical towards vaccination. Our children receive the vaccinations from the Child Health Care Centre, but after every vaccination our children get a restoring treatment, according to the anthroposophy."*

[1] *Authors' note: DES or diethylstilbestrol, was an artificial hormone prescribed worldwide before 1975 to pregnant women to prevent miscarriage; it was found to cause vaginal cancer in daughters. Herbst AL, Ufelder H, Poskanzer DC, Longo LD. Adenocarcinoma of the vagina. Association of maternal stilbestrol therapy with tumor appearance in young women. N Engl J Med 1971;284:878-81.*

"fear of side effects/harmful consequences" (51%), "just having a bad feeling about it" (46%) and "the vaccine was not thoroughly tested" (39%). This is illustrated by quote 1 to 6 from *Table 2*, which describes quotes from the in-depth interviews with decliners. Another reason for declining the H1N1 vaccination was "no trust in effectiveness of the vaccine" (35%) (quote 7). Thirty-four percent reported "contradictory messages in the media" as a reason for declining vaccination (quote 8,9), and 31% reported "no need to vaccinate have my child vaccinated against a mild flu" (quote 10,11). Sixteen percent reported "no trust in the government" as a reason for declining vaccination (quote 12,13), and 15% reported that their "child is never sick" (quote 14). Ten percent mentioned principle convictions (religion) or belief in alternative medicine (homeopathy, anthroposophy) (quote 15,16).

Table 3 details decliners' risk perception, feelings of doubt and regret, social influence, information-seeking behavior, and future vaccination intention, according to demographic characteristics. Thirty-eight percent of decliners reported that it would be (very) severe for them if their child had been infected with H1N1. Older parents (›30 years), those with a higher educational level, and native Dutch parents were less likely to report a high perceived severity of H1N1 for their child. One-quarter of the decliners believed that their child was susceptible to H1N1, and respondents with an intermediate educational level and immigrants were less likely to report a high perceived susceptibility of their child. Of the decliners, 63% expressed doubts about vaccinating their child. These doubts were more often reported by female decliners, those with a higher educational level, and immigrants. Most decliners did not regret their decision, although decliners with a lower educational level and immigrants more often reported feelings of regret.

Table 3. Risk perception, feelings of doubt and regret, social influence, information-seeking behavior, and vaccination intention of parents who declined H1N1 vaccination, by demographic characteristics (n=1900)

	Gender			Age		
	Male	Female	P-value	≤ 30 yrs	>30 yrs	P-value
1. Perceived risk of Influenza A (H1N1)						
How severe would it be for you, if your child had been infected with Mexican flu?						
Severe / very severe	37%	38%	ns	43%	36%	0.01
Do you think your child was susceptible to Mexican flu?						
Quite susceptible / very susceptible	25%	25%	ns	22%	26%	ns
2. Feelings of doubt and regret						
Did you have any doubts about vaccinating your child against Mexican flu?						
Some / many doubts	58%	65%	0.01	63%	64%	ns
Did you have any regrets of not vaccinating your child?						
Some / many regret	3%	2%	ns	2%	2%	ns
3. Social influence						
Did you ask advice from other people about vaccinating your child?						
Yes	62%	74%	<0.001	75%	70%	0.05
If yes; Was this advice of influence on your decision not to vaccinate your child?						
Probably / certainly	39%	37%	ns	33%	39%	ns
4. Information-seeking behavior						
Have you actively sought information about vaccination against Mexican flu?						
Yes	77%	76%	ns	74%	77%	ns
Did you visit Internet sites critical of vaccination?						
Yes	27%	25%	ns	26%	25%	ns
Did you consider information of the government (i.e. Ministry of Health, National Institute of Health and the Environment) regarding the Mexican flu to be reliable?						
Reliable / very reliable	18%	14%	ns	12%	15%	ns
5. If the government recommends vaccination (i.e. against a novel influenza virus) in the coming years, do you think you will have your child vaccinated?						
Probably/certainly	15%	9%	<0.001	7%	11%	0.02

[†] *lower educational level (i.e. primary education, lower general/vocational education or less);*

[‡] *intermediate educational level (i.e. secondary general or vocational education);*

[₮] *higher educational level (i.e. higher professional education or university);*

ns = not significant. P-value were derived by Chi-squared tests.

	Educational level				Ethnicity			Overall	
	Lower†	Intermediate‡	Higher₸	P-value	Native Dutch	Immigrant	P-value	%	n/ntot
	47%	40%	31%	‹0.001	29%	57%	‹0.001	38%	(616/1629)
	24%	22%	29%	0.01	29%	17%	‹0.001	25%	(417/1658)
	55%	65%	68%	‹0.001	61%	69%	0.001	63%	(1198/1889)
	5%	2%	1%	‹0.001	1%	6%	‹0.001	2%	(40/1866)
	64%	73%	74%	0.001	68%	80%	‹0.001	72%	(1355/1896)
	37%	32%	42%	0.006	35%	41%	0.04	38%	(498/1329)
	68%	74%	81%	‹0.001	75%	77%	ns	76%	(1439/1893)
	24%	24%	28%	ns	23%	32%	‹0.001	26%	(483/1885)
	13%	13%	17%	0.03	15%	14%	ns	15%	(271/1851)
	11%	9%	10%	ns	8%	13%	0.001	10%	(184/1869)

The majority of the decliners (72%) solicited advice from their social network about vaccinating their child. The most reported sources for advice among decliners were family (59%), friends (55%), and/or general practitioners (34%; data not shown). Female decliners, those aged younger than 30 years, those with a higher educational level, and immigrants were more likely to ask advice from their social network. Only 38% of the parents who solicited advice from their social network reported that this advice was influential. Higher educated parents and immigrants were more likely to report a social influence on their vaccination decision.

Three-quarters of decliners had actively sought information about H1N1 vaccination. Parents with a higher educational level more often sought information. One-quarter of the decliners visited Internet sites critical of vaccination; immigrants visited these

critical Internet sites more often than native Dutch decliners. Only 15% of the decliners considered governmental information about H1N1 to be reliable. Parents with a higher educational level more often reported governmental information to be reliable.

Although 93% of the decliners had their child vaccinated against other diseases following the NIP (data not shown), only 10% reported a high intention to vaccinate their child if the government recommends vaccination (i.e. against a new influenza virus) in the coming years. Females, younger parents (≤ 30 years), and native Dutch parents were less likely to accept vaccination in the coming years.

Comparison of accepters and decliners

We detected the following significant differences between the accepters and the decliners. Accepters more often reported negative feelings after their vaccination decision (8% versus 2%, $p<0.001$) and more social influence on their vaccination decision (58% versus 38%, $p<0.001$). Decliners more often reported feelings of doubt about the vaccination decision (63% versus 51%, $p<0.001$) and more information-seeking behavior (76% versus 56%, $p<0.001$). Furthermore, decliners more frequently solicited advice from their social network than accepters (72% versus 61%, $p<0.001$). Adjusting for differences in gender, age, educational level, and ethnicity between accepters and decliners in a logistic regression model did not influence these outcomes (data not shown).

Discussion

With the aim of optimizing response rates in future vaccination campaigns, we studied underlying reasons for vaccine (non-)acceptance, risk perception, feelings of doubt and regret, social influence, and information-seeking behavior of parents in the Netherlands who accepted or declined H1N1 vaccination for their healthy child.

A clear strength of this study is that it provides insight into the decision-making process of not only parents who accepted H1N1 vaccination for their child, but also parents who declined this vaccination. In addition to a quantitative survey of decliners, qualitative in-depth interviews of these participants were also carried out to obtain more detailed information about the reasons for declining. Furthermore, the response rate for the accepters was reasonably high (estimated by the interviewers at 75% in Rotterdam city and 90% in Vlaardingen) and sample sizes were large enough to detect significant differences in outcome measures between accepters and decliners and between demographic subgroups (gender, age, educational level and ethnicity).

This study also has some limitations. First, our study population was not fully representative for the accepters and decliners in (the southwestern area of) the Netherlands. For the decliners the response rate was rather low (19%), likely because parents who declined vaccination may have been less motivated to participate in this study. However, 19% is not that low compared to other similar studies [37,38]. No data were obtained from non-responders, bringing into doubt whether our results can be generalized to all parents who declined H1N1 vaccination in the Netherlands. Data among accepters were gathered in Rotterdam city and a surrounding municipality (Vlaardingen), with overrepresentation

of Rotterdam city. Additional analyses showed that respondents from Rotterdam city were younger, lower educated and more of non-Dutch descent compared to respondents from the surrounding municipality. This may have led to an overestimation of feelings of doubt and regret, influence of social network and information-seeking behavior when generalizing the results to the entire region or country. Second, data on accepters were collected immediately after the second vaccination round in December 2009, because it was not feasible to organize data collection after the first vaccination round at the end of November 2009. However, decision making process of full accepters (parents who accepted 2-dose vaccine) may differ from partial accepters (parents who accepted only one dose vaccine). Data on decliners were collected six months after the vaccination campaign, which may have led to some recollection bias. Furthermore, in the months after the vaccination campaign the number of cases remained relatively limited, the government announced that the virus had largely run its course, and media attention considerably decreased [39]. This may have potentially influenced survey answers among decliners (for example regarding feelings of doubt and regret). Third, the validity of our questionnaires could not be tested through a test-retest design, because the pandemic was ongoing and perceptions were not stable over time. Fourth, this study has a cross-sectional design, and can describe changes in neither the decision-making process over time nor in causal pathways (for example, does information-seeking lead to a critical attitude towards vaccination). Lastly, data on accepters were collected via exit interviews and data on decliners were gathered with questionnaires by post and in-depth interviews by telephone. The use of different data collection methods may have led to some bias in the results, i.e. personal exit interviews may have led to more social desirability answers compared to sending questionnaires by post.

Fear of side effects was the most important reason for declining H1N1 vaccination. Other studies also concluded that concerns about vaccine safety are one of the most important reasons for the public to decline H1N1 vaccination [21,31,32,40,41]. During the pandemic, the Dutch government did not prominently transmit information about possible vaccine side effects, in an effort to avoid public anxiety [42]. However, doubts about vaccine safety and effectiveness were discussed in the media, not only by vaccine-resistant groups but also by some critical experts. As our study shows, a substantial proportion of parents experienced “contradictory messages in the media”, that negatively influenced their vaccination decision. The media tend to focus more on the potential risks of vaccination than on its benefits, which has a negative impact on vaccination uptake as also described in other studies [32,41]. However, the media play a key role in public perceptions of the vaccine and are an important source of information for the public during outbreaks of infectious diseases [33]. Therefore, it is important to frequently inform the media from the beginning of an outbreak, thereby preventing public misconceptions and keeping trust in health authorities.

To enable parents to make an informed decision, health authorities must provide comprehensive information, including information about uncertainties and risks of preventive measures. This recommendation is in line with an evaluation of the Dutch H1N1 approach, which concluded that the government could have had prevented social unrest and contradictory media messages regarding vaccine side effects, if they had been transparent and had explicitly related the (probably small) risk of vaccine side effects [42]. A number

of studies describe the importance of vaccine risk/benefit communication and the development of communication tools [43,44]. We recommend that health authorities improve risk/benefit communication and invest in the development and implementation of effective vaccine risk/benefit communication tools for future vaccination campaigns.

Compared to the accepters, parents who declined H1N1 vaccination more often experienced feelings of doubt and more often asked advice from their social network, but less often reported being influenced by this advice. The accepters were more likely to have their child vaccinated because they followed the mainstream. Other studies described this principle as "science by consensus" - if many people make the same claim, it must be true [32,45]. The decliners deviated from the social norm, which made it more difficult to decide to not have their child vaccinated. Furthermore, decliners have perhaps made less of a decision than accepters, because parents who declined vaccination could change their minds and had the opportunity to catch-up the vaccinations, whereas parents who accepted vaccination for their child could not go back and undo it.

Aside from family and friends, general practitioners were an important source of advice, an observation comparable to those from other studies that describe the general practitioner as an important and trustworthy source of information for parents regarding childhood vaccinations [46,47]. It is necessary that the information and advice from general practitioners be in line with the information and advice of local and national health authorities. Unambiguous information from various institutes and experts will prevent public misconceptions and confusion. Furthermore, it has been advocated that general practitioners, who are role models for the public, themselves should be vaccinated in order to prevent transmission of the virus to vulnerable patients [48]. During the 2009 A (H1N1) pandemic vaccination uptake among Dutch general practitioners was high; 85% of the general practitioners were vaccinated against the H1N1 virus [49].

Information-seeking behavior was rather high, with over half of the accepters and three-quarters of the decliners who actively sought information. Sporton and Francis describe three different responses of parents on vaccination decision process: a routine response, an emotional response, and delaying the decision by entering a questioning stage followed by a cyclical process of seeking and evaluating information [50]. This last response of parents was mostly found in our study, and for these parents it is important to have access to reliable information sources. A number of studies have indicated that non-scientific sources such as the media or statements of politicians can have a large effect on parental vaccination decisions [32,47]. During future vaccination campaigns, health authorities should refer to reliable information sources that are accessible to the general public."

Differences between native Dutch and immigrant parents were observed; immigrant accepters and decliners more often expressed feelings of doubt and regret about the vaccination decision, more often solicited advice from their social network, and were more often influenced by this advice. This could be related to the lack of providing information in native languages, other than Dutch. However, ethnic differences in vaccination decision making have been described in several studies regarding influenza as well as other diseases, but these differences do not give an uniform picture [21,25,29,30,51-53]. A

study among Chinese people in Europe concluded that for ethnic minorities, family and friends are the most frequently consulted sources of information during outbreaks of infectious diseases, and that minorities have significantly more confidence in information from family and friends than from doctors or governmental institutes [54]. Ethnic minority groups may require a special strategy for risk communication that differs from the general population, suggesting that health authorities should take this aspect into account when designing future vaccination campaigns.

Conclusion

To optimize response rates in future vaccination campaigns, it is important that health authorities provide more information to the public about vaccine benefits and risks, information that should be tailored to specific risk groups. Therefore, health authorities should invest in the development and implementation of effective vaccine risk/benefit communication tools. Furthermore, it is critical to gain insight into the information needs of the general public during future vaccination campaigns. Information-seeking behavior during outbreaks of infectious disease is often high; health authorities should refer to reliable information sources to prevent misconceptions and to build trust in public health authorities. Only then are parents able to make informed decisions based on reliable information.

Competing interests
The authors declare that they have no competing interest.

Authors' contributions
All authors contributed to the study design. MB, DB, and HV played a main role in the data collection. Data analysis was performed by MB and HV. MB and HV wrote the first draft of the manuscript; DB, JvS, and JHR critiqued the manuscript and contributed to further drafts. HV is the guarantor. All authors read and approved the final manuscript.

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CHAPTER 5

Perceptions and behavioural responses of the general public during the 2009 Influenza A (H1N1) pandemic:

a systematic review

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Abstract

The public plays an important role in controlling the spread of a virus by adopting preventive measures. This systematic literature review aimed to gain insight into public perceptions and behavioral responses to the 2009 Influenza A (H1N1) pandemic, focusing on trends over time and regional differences. We screened 5498 articles and identified 70 eligible studies from PubMed, Embase, and PsychINFO. Public misconceptions were apparent regarding modes of transmission and preventive measures. Perceptions and behaviors evolved during the pandemic. In most countries, perceived vulnerability increased, but perceived severity, anxiety, self-efficacy and vaccination intention decreased. Improved hygienic practice and social distancing was practiced most commonly. However, vaccination acceptance remained low. Marked regional differences were noted. To prevent misconceptions, it is important that health authorities provide up-to-date information about the virus and possible preventive measures during future outbreaks. Therefore, they should continuously monitor public perceptions and misconceptions. Because public perceptions and behaviors varied between countries during the pandemic, risk communication should be tailored to the specific circumstances of each country. Finally, the use of health behavior theories in studies on public perceptions and behaviors during outbreaks would greatly facilitate the development of effective public health interventions that counter the effect of an outbreak.

Introduction

In 2009, a new strain of Influenza A (H1N1) spread rapidly around the world and caused the first global influenza pandemic of the 21th century. The "early phase" started in April 2009, with outbreaks in Mexico and the United States (US). The World Health Organization (WHO) declared it a "public health emergency of international concern" [1]. On 27 April, 2009, the first cases were confirmed in Europe [2]. The WHO then declared a phase 4 pandemic alert [3]. Two days later, 148 cases were reported in nine different countries. Furthermore, seven deaths were reported in Mexico and one in the US [4]. The WHO responded by raising the pandemic alert to level 5 [5]. On 10 June, 2009, 27 737 cases and 141 deaths were reported in 74 countries [6]. During the early phase, most countries implemented measures according to a "containment/delaying" strategy, which aimed to limit the spread of the virus. This strategy included the use of antiviral drugs for early treatment of cases and/or prophylaxis of close contacts, isolation of cases, and quarantining of contacts. The "pandemic peak phase" started on 11 June, 2009, when the pandemic alert was raised to phase 6 [7]. In the second half of June, the first deaths in Europe and Asia were confirmed, and the first case of Oseltamivir (Tamiflu) resistance was found in Denmark [8,9]. On 31 July, 2009, 1154 deaths were reported in five of the six WHO regions [10]. During this peak phase, most countries were moving to a "mitigation" strategy, aimed at minimizing the impact of the pandemic by recommending personal protective measures, including frequent hand washing, covering the mouth when coughing, and social distancing (e.g., maintaining physical distance from people with flu symptoms and avoiding crowded places). In August 2009, the intensity of most outbreaks was similar to that of seasonal epidemics, and the virus did not mutate to a more pathogenic form. Therefore, on 10 August, 2009, the WHO declared a "post-pandemic phase" [11]. Finally, despite the end of the pandemic, the H1N1 vaccine first became available during the post-pandemic phase.

The general public plays an important role in controlling the spread of a virus and minimizing the impact of a pandemic by adopting government-recommended preventive measures. Theoretical models, like the Protection Motivation Theory, have suggested that behavioral action may be influenced by public perceptions of disease severity, personal susceptibility to the disease, effectiveness of recommended measures, and self-efficacy (confidence in the ability to perform the recommended measures) [12]. Public behavior may also be influenced by knowledge and more affective factors, like feelings of anxiety [13,14]. Insight into public perceptions and behaviors during a pandemic can provide useful information for risk communication. The Influenza A (H1N1) pandemic was a unique situation; it was characterized by changes in risk, publicity, and recommended measures during the different phases. This scenario provided a unique opportunity to gain insight into public perceptions and behaviors, changes over time, and differences between countries. From 2009 to 2012, studies were conducted worldwide on this topic. Systematic literature reviews were performed by Bish et al. [15,16], Blasi et al. [17], Brien et al. [18] and Nguyen et al. [19], but these examined predictors of behavior. In the present systematic literature review, we aim to describe public perceptions and behaviors with a special focus on (1) trends over time, and (2) differences between inhabitants of various countries.

Methods

Search strategy and search criteria
A systematic literature search for studies on public perceptions and behaviors during the pandemic was performed on 13 October, 2011, and updated on 14 December, 2012. We searched PubMed, Embase, and PsychINFO databases with predefined online search terms. We used terms that represented public perceptions of risk (perceived disease severity and vulnerability), feelings of anxiety, intentions to take preventive measures, and actual behavior. The online search terms are given in detail in the webextra file to the online version of this article (supplement 1).

Inclusion criteria were: studies that focused on the general population and measured actual perceptions and/or behaviors during the pandemic (publication date of 2009 or later). Data had to be obtained with a quantitative study methodology, and only articles published in the English language were included.

Studies were excluded when they targeted a specific group, like health care workers, parents, pregnant women, students, or patients at risk. Furthermore, we excluded editorials, letters (unless they provided data), posters, and qualitative studies.

We followed the PRISMA guidelines for the literature search and preparation of the paper [20]. Articles were screened (by MB) with the above criteria, and articles were excluded by title, abstract, or full text. A second author (HV) independently screened the full text articles for eligibility. Any disagreement between the reviewers was discussed and resolved by consensus. Quality of the included papers was assessed by creating a quality score based on response rate and sample methodology. In social/behavioral science response rates above 30% are indicated as appropriate. We gave scores for response rate varying from 1 (response rate ‹10% or not described); 2 (10%-30%), to 3 (›30%). Sample methodology was scored varying from 1 (convenient samples or not described); 2 (representative sample methodology for a defined geographic area), to 3 (representative sample methodology for the whole country). A quality score for each paper was created by adding up the scores for response rate and sample methodology, ranging from 2 (low quality) to 6 (high quality). In the results we describe those studies with a score of 2 or more on response rate and sample methodology. Except for studies describing trends over time, also lower quality studies are described, with a special note about response rate/ sample methology. Data from the eligible studies were extracted (by MB) and categorized according to the pandemic phase and region, as defined by the WHO [21]. Trends over time were extracted from follow-up studies or studies with multiple cross-sections, i.e. measuring real trends over time. Regional differences were, mostly, extracted from those studies that included multiple countries/regions. These data are available as a webextra file to the online version of this article (supplement 2-8).

Results

The total search identified 5498 records, and 5385 were excluded on the basis of title and/or abstract. A total of 113 full text articles were assessed, and 70 met the final inclusion criteria *(Figure 1)*. The characteristics of the studies included in this review are described in *Table 2*. Studies were conducted in Europe (n=23), Asia (n=18), the US (n=14), Australia (n=8), Eastern Mediterranean (n=3), North America (n=1); three studies collected data in more than one country/region. Most studies collected data during the post-pandemic phase only (n=38), some collected data over two or more phases (n=18). The number of respondents per study ranged from 186 to 22 050, with response rates of 3 to 98%. Most studies were telephone-based surveys (n=39); most used a representative sampling methodology for the whole country (n=35) or for a defined geographic area (n=18), and most used a cross-sectional design (n=60). Ten studies used a time series design with multiple cross-sections (range 2-36), and ten studies followed the same respondents over time. Sixteen studies described one or more specific behavioral theory in the study rationale or for development of the questionnaire. Based on the quality assessment, most studies reached a quality score of 5 or 6 (n=46). *Table 3* presents the included studies (reference numbers) per determinant.

Figure 1 Systematic review process

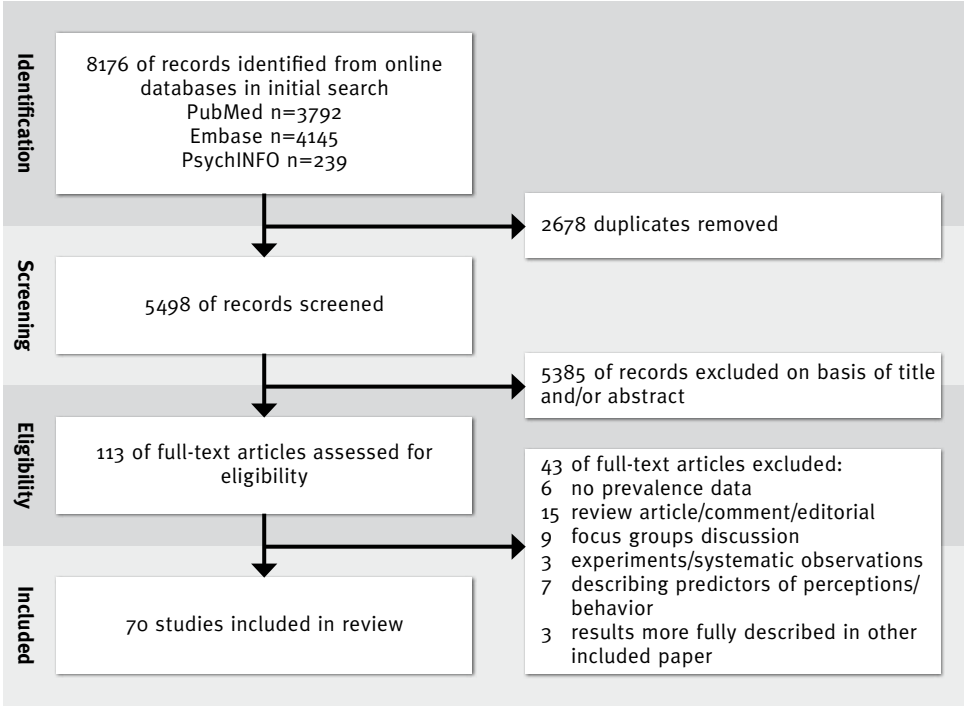

Table 2. Characteristics of studies included in review (n=70)

Study - Country	Phase of data collection‡	n	Response rate	Survey method
1. Aburto[22] - Mexico	1,2	2666	83%	Face to face
2. Agüero[23] - Spain	3	800-827	33-34%	Telephone
3. Balkhy[24] - Saudi Arabia	3	1548	97%	Face-to-face
4. Bangerter[25] - Switzerland	1,3	602	40-63%	Paper
5. Blank[26] - Mexico, Germany, France, United States, China	3	2500	5-33%	Telephone
6. Böhmer[27] - Germany	3	2493-22 050	56%	Telephone
7. Brown[28] - Australia	2,3	1292	42%	Telephone
8. Bults[29] - Netherlands	1,2,3	456-934	59-79%	Internet
9. CDC[30] - United States	3	207	80%	Face to face
10. Cowling[31] - Hong Kong	1,2,3	504-1404	66-75%	Telephone
11. Dhand[32] - Australia	2	510	Not described	Face-to-face + paper
12. Eastwood[33] - Australia	3	830	72%	Telephone
13. Ferrante[34] - Italy	3	4047	83%	Telephone
14. Galarce[35] - United States	3	1569	66%	Internet
15. Gaygisiz[36] - Turkey	3	1045	79%	Face-to-face
16. Gidengil[37] - United States	1,2,3	1874-2504	64-73%	Internet
17. Gilles[38] - Switzerland	1,3	950-601	25%	Not described
18. Goodwin[39] - Malaysia & Europe	1	Malaysia 180 Europe 148	Malaysia 90% Europe not described	Malaysia paper Europe internet
19. Goodwin[40] - Europe	1	186	Not described	Internet
20. Horney[41] - United States	3	207	80%	Face to face
21. Huang[42] - Taiwan	3	1079	69%	Telephone
22. Ibuka[43] - United States	1	1290	3%	Internet
23. Jehn[44] - United States	3	727	77%	Telephone
24. Jones[45] - United States	1	6249	Not described	Internet
25. Kamate[46] - India	2,3	791	98%	Paper
26. Kiviniemi[47] - United States	3	807	24%	Telephone
27. Kumar[48] - India	3	358	Not described	Paper
28. Kumar[49] - United States	3	2079	56%	Internet
29. Kwon[50] - Korea	3	1042	7%	Telephone
30. Lau[51] - Hong Kong	1	550	62%	Telephone
31. Lau[52] - Hong Kong	1	201-550	62%	Telephone
32. Lau[53] - Hong Kong	2	301	80%	Telephone
33. Lau[54] - Hong Kong	2	301	80%	Telephone
34. La Torre[55] - Italy	3	501	Not described	Internet
35. Leggat[56] - Australia	2,3	1292	42%	Telephone
36. Li[57] - United States	2,3	472-1007	47%	Internet
37. Liao[58] - Hong Kong	3	896-1433	63-87%	Telephone

	Representative sample methodology for the whole country (or defined population)?	Study design[τ] (study rounds)	Behavioral theory described[#]	Quality score based on response rate and sample methodology
	Y (3 cities)	CS (1)	None	5
	Not described	CS (2)	None	4
	Y (2 cities)	CS (1)	None	5
	Y	FU (2)	None	6
	Y (US, France, Germany, 3 largest cities in China, 3 largest cities in Mexico)	CS (2)	None	6
	Y	FU (2)	None	6
	Y (1 state)	CS (1)	None	5
	Y	FU (3)	PMT,HBM	6
	Y (2 counties)	CS (1)	None	5
	Y	CS (13)	None	6
	N	CS (1)	None	2
	Y	CS (1)	None	6
	Y	CS (1)	None	6
	Y	CS (1)	None	6
	N	CS (1)	None	4
	Y	FU (10)	None	6
	Y	FU (2)	None	5
	N	CS (1)	None	2
	N	CS (1)	None	2
	Y (2 counties)	CS (1)	None	5
	Y	CS (1)	HBM	6
	Y	CS (1)	HBM,PAPM	4
	Y (1 state)	CS (1)	RCF	5
	N	CS (1)	None	2
	N	CS (1)	None	4
	Y (1 state)	CS (1)	None	4
	N	CS (1)	None	2
	Y	CS (1)	SEM	6
	Y	CS (1)	None	4
	Y	CS (1)	None	6
	Y	CS (3)	None	6
	Y	CS (1)	None	6
	Y	CS (1)	None	6
	N	CS (1)	None	2
	Y (1 state)	CS (1)	None	5
	Y (4 cities)	FU (2)	HBM,PMT,TRA,TPB	5
	N	FU (2)	TPB	4

Table 2. Characteristics of studies included in review (n=70, *continued*)

Study - Country	Phase of data collection‡	n	Response rate	Survey method
38. Lin[59] - China	3	+/-3500	47%	Telephone
39. Marshall[60] - Australia	2009¥	1961	65%	Telephone
40. Maurer[61] - United States	3	917	74%	Internet
41. Maurer[62] - United States	1	2067	54%	Internet
42. Miao[63] - Taiwan	3	1079	69%	Telephone
43. Myers[64] - United Kingdom	3	362	Not described	Internet + paper
44. Naing[65] - Malaysia	3	272	97%	Face to face
45. Prati[66] - Italy	3	1010	25%	Telephone
46. Quinn[67] - United States	1,2	1543	62%	Internet
47. Raude[68] - France	3	1003	46%	Telephone
48. Renner[69] - Germany	3	285-397	Not described	Internet
49. Reuter[70] - Germany	3	429-629	6%-68%	Internet
50. Rubin[71] - United Kingdom	1	997	3%	Telephone
51. Rubin[72] - United Kingdom	1,2,3	1047-1173	8%-11%	Telephone
52. Schwarzinger[73] - France	3	2253	11%	Internet
53. Seale[74] - Australia	1	620	Face to face 85% Email 61%	Face to face + email
54. Seale[75] - Australia	3	27	47%	Face to face
55. Setbon[76] - France	2	1001	Not described	Telephone
56. Setbon[77] - France	3	1003	46%	Telephone
57. Steelfisher[78] - United States	1,2,3	Not described	Not described	Telephone
58. Steelfisher[79] - Japan, Mexico, Argentina, United States, UK	3	900-911	12-21%	Telephone
59. Sypsa[80] - Greece	3	1000	Not described	Telephone
60. Taylor[81] - Australia	3	2038	57%	Telephone
61. Vaux[82] - France	1,2,3	10091	56%	Telephone
62. Velan[83] - Israel	3	501	32%	Telephone
63. Walter[84] - Germany	3	+/-1000	45%	Telephone
64. Walter[85] - Germany	3	+/-1000	Not described	Telephone
65. Weerd[86] - Netherlands	1,2,3	+/- 500	52-73%	Telephone
66. Wong[87] - Malaysia	2,3	1050	60%	Telephone
67. Wong[88] - Malaysia	2,3	1050	69%	Telephone
68. Wong[89] - Malaysia	2,3	1050	60%	Telephone
69. Wong[90] - Malaysia	3	1025	67%	Telephone
70. Yi[91] - Japan	3	428	39%	Paper

‡ *Phase 1 = early phase (end of april-11 June 2009); phase 2 = pandemic peak phase (11 June-10 August 2009); phase 3 = post-pandemic phase (from 10 August 2009 onwards).* [τ]

CS = cross-sectional, FU = follow-up.

[#] *Specific behavioral theory described in introduction and/or used for developing questionnaire;*

PMT = Protection Motivation Theory;

HBM = Health Belief Model;

PAPM = Precaution Adoption Process Model;

	Representative sample methodology for the whole country (or defined population)?	Study design[τ] (study rounds)	Behavioral theory described[#]	Quality score based on response rate and sample methodology
	Y (7 urban regions, 2 rural areas)	CS (3)	None	5
	Y (1 state)	CS (1)	None	5
	Y	CS (1)	None	6
	Y	CS (1)	None	6
	Y	CS (1)	HBM	6
	N	CS (1)	TPB,HBM	2
	N	CS (1)	HBM	4
	Y	CS (1)	None	5
	Y	CS (1)	TDM	6
	Y	CS (1)	None	6
	N	FU (2)	PMT	2
	N	FU (3)	None	4
	Y	CS (1)	None	4
	Y	CS (36)	PMT,HBM,EPPM	5
	Y	CS (1)	None	5
	N	CS (1)	None	4
	N	CS (1)	None	4
	Y	CS (1)	HBM,SRM	4
	Y	CS (1)	None	6
	Not described	CS (20)	None	2
	Y	CS (1)	None	5
	Y	CS (1)	None	4
	Y (1 state)	CS (1)	None	5
	Y	CS (1)	None	6
	Y	CS (1)	None	6
	Y	CS (13)	None	6
	Y	CS (13)	None	4
	Y	CS (16)	TCM,PMT	6
	Y (1 city)	CS (1)	None	5
	Y (1 city)	CS (1)	None	5
	Y (1 city)	CS (1)	HBM,CSM	5
	Y (1 city)	CS (1)	None	5
	Y (4 wards, 1 city in Tokyo)	FU (2)	None	5

RCF = Risk Communication Framework;
SEM = Social Ecological Model;
TRA = Theory of reasoned action;
TPB = Theory of Planned Behavior;
TDM = Trust Determination Model;
EPPM = Extended Parallel Process Model;
SRM = Self-regulation Model;
TCM = Trust and Confidence Model;
CSM = Common Sense Model.
[¥] *Specific data collection period not defined, results included in description pandemic peak phase.*

Public knowledge about Influenza A (H1N1)

High knowledge levels about the main modes of transmission of the H1N1 virus (i.e., through droplets and/or close contact with infected people) were observed among the general public in different countries during the various pandemic phases [22,24, 29,31,53,59,60,88,90,91] (webextra file, supplement 2). Nevertheless, a number of misconceptions and/or unconfirmed beliefs were apparent. For example, about other modes of transmission of the H1N1 virus, such as transmission through an oral-fecal route, across long distances, via water sources, via insect bites, by eating improperly cooked pork or pork products or via a sexual route [24,31,52,88,90]. Changes in influenza terminology ("swine flu" and "H1N1") were reported to have caused some confusion, as reported in a study conducted in the US (Arizona) during the post-pandemic phase [44]. Furthermore, suboptimal knowledge levels were observed regarding recommended preventive measures. For example, a substantial proportion of Hong Kong respondents during the early phase erroneously believed that the government recommended that the public should regularly use facemasks in public venues and avoid visiting crowded places [51]. Although high awareness of personal hygiene measures were observed in studies in the US (Arizona) [44], Italy [34], and China (7 urban regions and 2 rural areas) [59] during the post-pandemic phase, interpretation of these general recommendations varied widely [47]. In particularly, regarding the H1N1 vaccine, part of the public in the Netherlands [29], Hong Kong [52,53], and South Australia [60] respectively had the misconception that during the early and pandemic peak phases a vaccine was available; that a seasonal influenza vaccination could effectively prevent H1N1; and that the efficacy of the H1N1 vaccination had been confirmed in clinical trials.

Perceived severity of Influenza A (H1N1)

Declining trends were observed in the perceived severity of H1N1, as reported in follow-up studies or studies with multiple cross-sections conducted in the US [37], Netherlands [29], and Hong Kong [31,52] (webextra file, supplement 3). For example, the study in the Netherlands described that the percentage of respondents that perceived high severity decreased from 80% during the early phase in May to 39% during the post-pandemic phase in August [29]. A Hong Kong study reported that perceived severity of H1N1 was high in April 2009, but declined to lower levels by the time the local epidemic began [31]. Also in studies with a low response rate (US) [43] and using convenience sampling (Germany) [70] declining trends in perceived severity were observed.

Although declining trends were observed in all regions, differences were found in the absolute levels of perceived H1N1 severity. For example, Blank et al. [26] conducted a study in five countries late within the post-pandemic phase and described that perceived severity of H1N1 was higher in Mexico (3 largest cities), with over half of the respondents (51%) considering the severity of H1N1 to be serious, compared to China (3 largest cities; 26%), US (19%), France (9%) and Germany (5%).

Perceived vulnerability to Influenza A (H1N1)

The perceived vulnerability among the general public increased over time during the early and pandemic peak phases, as reported in the US [37], Netherlands [29,86], and Hong Kong [31] (webextra file, supplement 4). For example, the US study reported that the mean perceived risk of contracting H1N1 increased over the summer with a peak in

September 2009 [37]. The study in the Netherlands described that in April, 2009, 18% of the respondents perceived that they were quite or very susceptible to infection with H1N1 which increased to 30% in August, 2009 [29]. Also a study with a low response rate (US) identified increasing trends in perceived vulnerability during the early phase [43]. Although increasing trends were observed during the early and pandemic peak phases, declining trends in perceived vulnerability were observed late within the post-pandemic phase, as reported in studies conducted in the US [37], Germany [84], and Italy [34].

Despite increasing trends in the early and pandemic peak phases, absolute levels of perceived vulnerability remained relatively low in most countries, even during the pandemic peak and post-pandemic phases [26,29,37,52,53,67,73,90,91]. Regional differences in perceived vulnerability were reported in a study by Blank et al. [26], conducted late within the post-pandemic phase. They described that perceived vulnerability was higher in Mexico (3 largest cities), with 35% of the respondents considering the risk of catching H1N1 as serious, compared to US (19%), China (3 largest cities; 15%), France (10%) and Germany (4%). Furthermore, studies conducted during the pandemic peak phase showed that respondents perceived themselves less likely to get infected with H1N1 compared to other individuals [29,31,53,67].

Feelings of anxiety regarding Influenza A (H1N1)

Studies that measured perceived anxiety tended to focus on two separate topics; the perceived anxiety about the pandemic/H1N1 virus in general; and the perceived anxiety about becoming personally infected (webextra file, supplement 5). The perceived anxiety about the pandemic/H1N1 virus in general showed decreasing trends in studies in the Netherlands [29] and Italy [34], reporting that the perceived anxiety waned in concert with the waning perception that the virus was an immediate threat. Comparable trends were observed in studies with a low response rate (US) [45] and using convenience sampling (Germany) [70]. The perceived anxiety about becoming personally infected increased, according to a UK study [72]; the percentage of respondents that were worried about becoming personally infected increased from 10-17%, during the early phase in May 2009, to 33% during the peak phase mid July 2009.

Perceived anxiety about the pandemic/H1N1 virus in general varied among different countries in the Western Pacific and Southeast Asia. During the pandemic peak phase, high anxiety levels were reported in studies conducted in Australia (Queensland) [56], with over 50% of respondents concerned about H1N1 while travelling, and in Malaysia (Kuala Lumpur) [88,89], with 73% of respondents being (slightly) fearful of H1N1 infection; but, in Hong Kong, anxiety remained fairly low, with most respondents reporting no anxiety [31]. Also in the Netherlands, anxiety levels were generally low [29]. The perceived anxiety of becoming personally infected varied regionally. Rather low levels were observed in studies conducted in Hong Kong [31,52], Australia [33,81], the UK [72], France [73], and Germany [84], whereas in the US the fear of personal infection remained fairly high [41,44].

Table 3 Included studies (reference numbers) on public perceptions and behavioral responses, by pandemic phase and WHO region†

	Early phase			
	The Americas	Europe & Eastern Mediterranean	Western Pacific & Southeast Asia	
Knowlegde (n=27)				
-modes of transmission	22	29	31	
-misconceptions/unconfirmed beliefs	-	29,39	31,51,52	
-awareness of flu prevention strategies	-	-	-	
-general knowledge level	-	-	-	
Perceived severity (n=24)				
-perceived severity	-	29	31,51,52,74	
-perceived fatality	37,43	-	51,52	
-severity compared to other ID±	45	-	51,52	
Perceived vulnerability (n=28)				
-perceived vulnerability	37,45	29,86	31	
-likelihood getting infected	43	29	52,74	
Feelings of anxiety (n=27)				
-anxiety about H1N1 (pandemic)	45	29,71	31	
-anxiety becoming infected	-	39,40,72	31,39,52	
Perceived (self)efficacy (n=17)				
-antiviral medication	-	29	74	
-face mask	-	29,71	52	
-hygiene measures	-	29,71	52,74	
-social distancing	-	29,71	52,74	
-vaccination	-	-	74	
-other measures	-	29	52	
Intention (n=41)				
-antiviral medication	43	29,86	74	
-face mask	-	29	52	
-hygiene measures	-	29,86	-	
-social distancing	-	29	52	
-vaccination	37,43,62	-	-	
-other measures	-	29,39	39,52	
Behavior (n=44)				
-antiviral medication	22,78	29	-	
-face mask	22,45,78	29	31	
-hygiene measures	22,45,78	29,71	31,52	
-social distancing	22,43,45,78	29,39,71	31,39,52	
-vaccination	-	-	-	
-other measures	22,78	29,39,71	39	

± *ID = Infectious Diseases;*

† *http://www.who.int/about/regions/en/index.html*

	Pandemic peak phase			Post pandemic phase		
	The Americas	Europe & Eastern Mediterranean	Western Pacific & Southeast Asia	The Americas	Europe & Eastern Mediterranean	Western Pacific & Southeast Asia
	-	29	31,32,53,60,88	44	24,29,55	31,42,48,59,65,90,91
	-	29	31,46,53,60,88	-	24,29,55,64	31,59,65,90
	-	-	60	30,41,44,47	34,55	59
	-	-	-	-	80	42,65,75
	67	29	31,46,53	26,61	24,26,29,36,69, 70,73,80	26,31,33,42,75,90
	37,67	-	53	37	-	90
	-	-	53	-	-	42,50
	37	29,86	31,88	26,37,44	26,29,36,84,86	26,31,42,75,90,91
	67	29	32,53	35,44	29,34,69,70,73,80	42,50,81
	67	29	31,56,60,88,89	49	29,34,70	31,59,90
	-	72	31,32	41,44	55,69,70,72,73,84	31,33,59,81
	-	29	46	-	29	-
	-	29	32,46	-	29,55	48
	-	29	32,46	47	29	-
	-	29	32,46	47	29	-
	-	29	46,53,54	47	29	42,50,75,90
	-	29	32,88	-	29	-
	67	29,86	-	-	29,86	-
	-	29	60	-	29	65,81
	-	29,86	-	47	29,86	65
	-	29	28,56,60	44,47	24,29,55	65,81
	37,67,78	29,76,86	53,60	30,37,41,44, 47,49,61,78	29,34,55,64,68,69, 72,73,77,80,85,86	33,42,50,58,65, 75,81,90,91
	-	29	-	-	29	-
	-	29	60,87,89	-	29	-
	-	29	31,87,89	79	23,24,29,55,77,79	31,48,79
	-	29	31,46,87,89	44,79	23,24,25,29,36, 55,66,77,79	31,48,59,63,79,91
	-	29	31,46,87,89	44,79	23,29,34,36,55, 66,77,79	31,48,59,79
	-	-	-	26,35,37,49, 57,61,79	23,26,27,38,66,68, 69,73,79,82,83,85	26,58,59,79,91
	-	29	32,87,89	44	23,24,29,36,55	48,81

Perceived efficacy of preventive measures
Studies conducted in the US (New York State) [47], Netherlands [29], and Hong Kong [52] showed that improving hygienic practice (i.e., more frequent hand washing, using tissues when coughing/sneezing, cleaning/disinfecting things) was perceived as most effective preventive measure (webextra file, supplement 6). Only one study in the Netherlands investigated trends over time in perceived efficacy of measures [29]. That study showed inconsistent patterns: the perceived efficacy of some measures, like antiviral medication, tended to increase at first, and then decrease later; other measures, like avoiding crowded places, tended to show the opposite pattern.

Perceived efficacy of vaccination was relatively high, although some variance was observed among countries. During the post-pandemic phase, vaccination against H1N1 was perceived as effective by 82% of respondents participating in a study in Taiwan [42], 81% in the US (New York State) [47], 76% in Malaysia (Kuala Lumpur) [90], to 53% in the Netherlands [29].

Perceived self-efficacy regarding H1N1 prevention
Perceived self-efficacy (confidence in the ability to prevent H1N1 infection or perform preventive measures) was measured in only four studies, two in Hong Kong [52,54], one in Malaysia (Kuala Lumpur) [88], and one in the Netherlands (data not shown) [29]. The studies conducted in Malaysia (Kuala Lumpur) [88], and the Netherlands [29], and one of the Hong Kong studies [52], measured trends over time in perceived self-efficacy to prevent H1N1 infection. They concluded that, during the early and pandemic peak phases, a decreasing percentage of respondents were confident that they or their family members could prevent an H1N1 infection in the next year. The study in the Netherlands showed that the perceived self-efficacy to perform preventive measures tended to decrease from May to August, 2009 [29].

Despite the declining trends, all four studies found relatively high levels of perceived self-efficacy to perform preventive measures [29,52,54,88]. For example, the study in the Netherlands reported that during the different pandemic phases, the majority of respondents felt confident in their ability to improve hygienic practice (88-91%), to seek medical consultation with the onset of flu symptoms (86-91%), and to get vaccinated against H1N1 (70-79%) [29]. The Hong Kong study reported that, during the pandemic peak phase, 77% of respondents believed that they or their family members would be able to get a H1N1 vaccination [54].

Intention to take measures
Declining trends were observed in intention to receive H1N1 vaccination, in particularly during the post-pandemic phase, as reported in studies conducted in the US [37], Italy [34], and the Netherlands [29] (webextra file, supplement 7). For example, the US study [37] reported that vaccination intention was highest at the beginning of the pandemic, decreased over time with the lowest point in January 2010. Also in two other studies with an unreported response rate, conducted in Greece [80] and Germany [85], decreasing trends in vaccination intention were observed.

During the early phase, the intention to improve hygienic practice, seek medical consultation at the onset of flu symptoms, and take antiviral medication was generally high, as

reported in studies conducted in the Netherlands [29] and Hong Kong [52]. Furthermore, in Hong Kong most respondents reported that they would comply with quarantine measures and, if infected, they would wear a facemask when going out [52]. During the pandemic peak and post-pandemic phases, the intention to take preventive measures remained relatively high in most countries, including the US (Arizona and New York State) [44,47], the Netherlands [29], and Australia (Queensland, New South Wales and South Australia) [28,60,81], particularly in improving hygienic practice and social distancing. During the pandemic peak, 40-77% of respondents in the studies included in this review reported that they were willing to accept an H1N1 vaccination if offered [29,37,53,60,86]. However, the intention to get vaccinated was highly sensitive to the availability of scientific evidence on efficacy and safety, the vaccination provider, and the cost. For example, in a US study [67], only 9% of respondents were willing to get a new vaccine that had not been approved; in a Hong Kong study [53], only 5% would accept a vaccination in the absence of data on efficacy and safety. During the post-pandemic phase, the intention to get vaccinated against H1N1 varied widely. As reported in studies conducted in the US [30,37,41,44,47,49,61], the intention to get vaccinated varied between 9% and 64%; in European studies, the intention to get vaccinated varied, with 17-27% in France [68,73,77], 10-36% in Italy [34], 56% in the UK [72], and 43-63% in the Netherlands [29,86]. Studies conducted in Asia [42,90,91] and Australia [33,81] reported vaccination intention rates between, respectively 57-78%, and 65-67%.

Actual behavior

Improved hygienic practice and social distancing were the most often reported preventive behaviors, as reported in studies conducted in Mexico [22,79], the US [44,79], Argentina [79], Saudi Arabia (Riyadh and Jeddah) [24], Europe [29,66,77,79], and Asia [31,52,59,63,79,87,89,91] (webextra file, supplement 8). A study in the Netherlands reported increasing trends in improving hygienic practice during the pandemic peak phase [29]. A study conducted in Malaysia reported increasing trends in staying at home, taking preventive medicine and wearing masks, whereas washing hands regularly declined from half August 2009 [87]. Furthermore, decreasing trends were observed regarding social distancing measures (e.g., avoiding public transport and crowded places) as reported studies conducted in Hong Kong [31,52], and Italy [34].

Regional differences were observed during the post-pandemic phase. As reported by Steelfisher et al. [79], improved hygiene practice was higher among respondents in Mexico, Argentina and the US, compared to Japan and the UK. The use of facemasks was higher among respondents in Mexico and Japan (resp. 71% and 63%), compared to Argentina (19%), the UK (11%) and US (8%) [79]. Furthermore, social distancing behaviors were higher among respondents in Mexico (33-69%) and Argentina (15-61%), compared to respondents in the US (4-56%), Japan (4-43%) and the UK (2-21%) [79]. Vaccination acceptance was rather low varying from 2% to 19% as reported in studies conducted in Europe [26,27,38,66,68,73,79,82], 10% to 25% in China [26,59] and Japan [79,91], 13% to 33% in Mexico [26,79], and 9% to 41% in the US [26,35,37,49,57,61,79].

Discussion

The public in the different countries was generally well informed about the main modes of H1N1 virus transmission, and the knowledge level remained relatively stable during the pandemic phases [22,24,29,31,53,59,60,88,90,91]. Nevertheless, there were a number of misconceptions and unconfirmed beliefs, for example, about recommended preventive measures, especially vaccination, and other modes of transmission of the H1N1 virus (e.g., oral-fecal and sexual routes, water sources, insect bites, and eating pork products) [24,31,47,51,52,53,60,88,90]. This was caused, in part, by changes in influenza terminology ("Mexican flu", "swine flu", and "H1N1"). During past outbreaks of infectious diseases (e.g., SARS and avian influenza), there were also public misconceptions and unconfirmed beliefs; these were associated with emotional distress of the general public [92,93].

Declining trends were observed in perceived severity and feelings of anxiety about the pandemic/H1N1 virus [29,31,34,37, 43,45,52,70]. This was probably caused by intense media attention in most countries in the early phase. Representatives of international and national health organizations were predicting worst-case scenarios with large numbers of fatalities based on influenza pandemics in the past. However, most local outbreaks of H1N1 turned out to be similar in intensity to that of seasonal flu epidemics, and the clinical picture of the disease was mild. This led to declining trends in perceived severity and feelings of anxiety.

Increasing trends were observed in perceived vulnerability during the early and pandemic peak phases [29,31,37,43,86]. This was consistent with the fact that the number of infected and fatal cases increased rapidly during these phases. Despite this increasing trend, the perception of perceived vulnerability remained relatively low in most studies [26,29,37,52,53,67,73,90,91]. Furthermore, most respondents believed that they were less likely to become infected with H1N1 than other people during the pandemic peak phase [29,31,53,67]. This suggested that, during the pandemic, the general public in most countries were unrealistically optimistic (or had an "optimistic bias") regarding the risk of contracting H1N1. This unrealistic optimism may have been influenced by the mild course of the H1N1 pandemic and the fact that people could protect themselves by taking preventive measures, which gave the general impression that the pandemic was under control.

Improving hygienic practice (i.e., more frequent hand washing, using tissues when coughing/sneezing, cleaning/disinfecting things) was perceived as more effective, compared to other non-pharmaceutical measures, like quarantining or facemask use [29,47,52]. Pharmaceutical measures, including vaccinations and antiviral medications, are generally very effective in preventing the spread and minimizing the impact of diseases. However, producing a vaccine against a new virus takes time, and resistance against antiviral drugs may occur; both of these factors occurred during the 2009 A (H1N1) pandemic. In the first phases of the pandemic, non-pharmaceutical measures were available and recognized by the WHO as potentially useful in reducing transmission of influenza [94]. A recent review of the efficacy of measures against influenza found evidence that hand hygiene and respiratory etiquettes reduced the spread of the virus [95]. Some studies have shown efficacy for other non-pharmaceutical measures, including quarantine or facemask, but correct implementation of these measures is often difficult, particularly for long periods of time [96,97].

Of the 48 studies included in this review, only four measured perceived self-efficacy regarding preventive measures (i.e., confidence in the ability to prevent H1N1 infection or perform preventive measures) [29,52,54,88]. Although self-efficacy is a construct within the Protection Motivation Theory, and comparable to "perceived behavioral control" in the Theory of Planned Behavior [98], this construct is not included in many other health behavioral theories. This may explain why only a few studies included perceived self-efficacy. Surprisingly, only around twenty percent (n=16) of the reviewed studies described one or more behavioral theories in the study rationale or for development of the questionnaire.

During the pandemic peak phase, the majority of respondents in most studies reported that they would be willing to accept a H1N1 vaccination, if offered [29,30,41,42,44,47,61,72,90,91]. However, the intention to get vaccinated was highly sensitive to the availability of scientific evidence on efficacy and safety, the vaccination provider, and personal cost [53,67]. Furthermore, declining trends were observed in intention to receive H1N1 vaccination, in particularly during the post-pandemic phase [34,37,80,85]. As reported in several studies, reasons for the low rates of vaccination intention included a belief that the vaccine might be unsafe, a fear of side effects, doubts about vaccine efficacy, a belief that the risk of infection was low, and a belief that, if infected, the illness would be mild [26,27,30,58,74,80]. Actual vaccination acceptance was much lower than expected, because the vaccine was not available until the post-pandemic phase, when the virus had run its course. Furthermore, the vaccination policies varied among (neighboring) countries; for example, there were differences in the target groups, the number of recommended doses, and the content of available vaccines [99]. Some countries may have faced logistical and organizational issues, which caused poor uptake of vaccination. These factors elicited public debate, fueled by the media, about whether the benefits of the H1N1 vaccine outweighed the possible risks.

Regional differences in actual behavior were also observed. For example, Steelfisher et al. [79] reported that improved hygiene practice, facemask use and social distancing was higher among respondents in Mexico compared to respondents of other countries. The regional differences in the actual behavior may have been due to differences in number of (fatal) cases and the information people received. Furthermore, in some countries, a specific preventive measure might be more acceptable than others. For example, in Mexico, the government advised citizens to use facemasks on public transport and the Mexican army distributed 6 million masks [100]. However, in other countries, facemask use was not widely recommended. In those countries, facemasks appeared to be associated with negative feelings, like disease victimization and stigmatization.

The present literature review had a number of limitations. First, some studies used a non-representative sampling methodology (e.g., convenient sampling), were conducted in a single state, city, or region, or had low response rates. This brought into question whether those results could be generalized to the general public of that country or region. Second, studies varied in the specific formulation of questionnaire items and answer scales. Some studies, for example, queried individuals about feelings of anxiety or worry specifically related to becoming infected with H1N1 [29,52]. Others used questionnaire items that surveyed more general feelings of anxiety [31,72]. For example, the State Trait

Anxiety Inventory (STAI) included questions regarding worry, tension, apprehension, and nervousness to quantify adult anxiety, with definitions that distinguished between state anxiety, trait anxiety, feelings of anxiety, and depression. Third, regional differences were, mostly, extracted from those studies including multiple countries. However, for perceived anxiety, (self-)efficacy and intention we assessed regional differences by comparing single-country studies, because no multi-country studies were available. Furthermore, it should be noted that, although the WHO declared each specific alert phase for the entire world, there was variation in the number of cases and deaths among different regions/countries. For example in Asia the timeline was slightly different and the actual peak occurred later, whereas in some countries there was a second peak of the epidemic in November/December, 2009. Therefore the phase announcements most likely had differential influences on public perceptions and behaviors. Fourth, most studies (n=39) were telephone-based surveys; fifteen were internet-based; seven were face-to-face interviews; four were paper-based; and four used a combination of these methods. Different data collection methods may have introduced biases, e.g., the telephone-based surveys may have elicited more socially desirable answers compared to internet-based surveys. Fifth, most studies had short data collection periods, and therefore, only provided an indication of the perceptions and behaviors of the public at that specific point during the pandemic. Sixth, we presented the main constructs of the Protection Motivation Theory. However, other health behavior theories describe constructs that may also influence public behavior, like perceived barriers and benefits, social influence (social norms/pressure), and trust in government [98,101]. Finally, some constructs were included in many studies, in different pandemic phases, and in different WHO regions, but other constructs were only measured in a few studies during a specific phase or in particular region. Therefore, it was difficult to extract the most important findings or identify certain general patterns.

Despite these limitations, the findings of this review provided useful information for risk communication during outbreaks of infectious diseases what can contribute to achieving successful changes in public behavior that reduce the spread and impact of disease. First, this review showed that public perceptions and behaviors are not stable and can evolve over a short period of time. During future outbreaks of (emerging) infectious diseases, health authorities should continuously monitor public perceptions and misconceptions and take this information into account when communicating with the public. Furthermore, health authorities should inform the public regularly about the course of the outbreak, what is known (the certainties), and what is unknown (the uncertainties); in addition, health authorities should be transparent about governmental decision-making. This is essential not only to instruct and motivate the public to take effective preventive measures, but also to build trust in public health authorities and to prevent misconceptions. Second, clear regional differences were observed in public perceptions and behaviors during the 2009 Influenza A (H1N1) pandemic. When preparing risk communication plans for future outbreaks of infectious diseases, we recommend that the information is tailored to the specific circumstances of each country, based on general guidelines provided by global agencies, such as the WHO. Studies that were conducted during past outbreaks can provide the basis for preparing an appropriate risk communication strategy for the next outbreak. Third, few studies in this review used a theoretical framework (e.g., a behavioral theory). We strongly recommend the use of health behavior theories when conducting studies on public perceptions and behavioral responses during

outbreaks of infectious diseases. This approach is more likely to provide profound insights into perceptions, behaviors, and their underlying correlations. Moreover, the use of health behavior theories in studies on public perceptions and behavioral responses would greatly facilitate the development of effective public health interventions that counter the effect of an outbreak.

Panel: Research in context

Systematic review

We searched Pubmed, Embase and PsychINFO databases for articles published from 2009 till 14 December 2012, with search terms that represented public perceptions of risk (perceived disease severity and vulnerability), feelings of anxiety, intentions to take preventive measures, and actual behavior. We included studies that focused on the general population and that measured actual perceptions and/or behaviors during the pandemic. Data had to be obtained with a quantitative study methodology, and only articles published in the English language were included. Quality of included articles was assessed based on response rate and sample methodology. No comparable reviews have ever been performed.

Interpretation

Our review is the first describing public perceptions and behaviors during the Influenza A (H1N1) pandemic with a special focus on 1) trends over time, and 2) differences between inhabitants of various countries. This review showed that public perceptions and behaviors are not stable and can evolve over a short period of time. Public misconceptions were apparent regarding modes of transmission and preventive measures. To prevent misconceptions during future outbreaks, it is important that health authorities provide up-to-date information about the virus and possible preventive measures. Therefore, they should continuously monitor public perceptions and misconceptions. Because public perceptions and behavioral responses varied between countries during the pandemic, risk communication should be tailored to the specific circumstances of each country.

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Author contributions

All authors contributed to the design of the study. MB and HV reviewed potentially eligible studies. MB and HV wrote the first draft of the manuscript; DB and JHR critiqued the manuscript and contributed to further drafts. All authors read and approved the final manuscript.

Conflict of interest

We declare no conflict of interest.

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CHAPTER 6

Q fever in the Netherlands: public perceptions and behavioural responses in three different epidemiological regions:

a follow-up study

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Abstract

Background
Over the past years, Q fever has become a major public health problem in the Netherlands, with a peak of 2,357 human cases in 2009. In the first instance, Q fever was mainly a local problem of one province with a high density of large dairy goat farms, but in 2009 an alarming increase of Q fever cases was observed in adjacent provinces. The aim of this study was to identify trends over time and regional differences in public perceptions and behaviours regarding Q fever in the Netherlands.

Methods
One cross-sectional survey (2009) and two follow-up surveys (2010, 2012) were performed. Adults, aged ≥18 years, that participated in a representative internet panel were invited (survey 1, n=1347; survey 2, n=1249; survey 3, n=1030).

Results
Overall, public perceptions and behaviours regarding Q fever were consistent with the trends over time in the numbers of new human Q fever cases in different epidemiological regions and the amount of media attention focused on Q fever in the Netherlands. However, there were remarkably low levels of perceived vulnerability and perceived anxiety, particularly in the region of highest incidence, where three-quarters of the total cases occurred in 2009.

Conclusion
During future outbreaks of (zoonotic) infectious diseases, it will be important to instil a realistic sense of vulnerability by providing the public with accurate information on the risk of becoming infected. This should be given in addition to information about the severity of the disease, the efficacy of measures, and instructions for minimising infection risk with appropriate, feasible preventative measures. Furthermore, public information should be adapted to regional circumstances.

Keywords
Zoonotic infections; Q fever; risk perception; behavioural responses; general public; risk communication

Background

Q fever is a zoonosis caused by the bacterium Coxiella burnetii. The primary reservoirs of the bacterium are farm animals, including goats, sheep, and cattle [1]. Acute Q fever typically presents as an influenza-like illness, but severe infections, like pneumonia and/or hepatitis, may also occur [2,3]. Approximately, 1-5% of all Q fever cases may progress to a chronic infection, which often leads to life-threatening endocarditis. Although Q fever is associated with substantial morbidity, mortality is uncommon (1-2% of cases) [1,4].

In the Netherlands, the first community outbreak of Q fever occurred in 2007, in the southern region of the Netherlands [5,6]. By the end of that year, 168 human Q fever cases were reported [7]. The second wave, in 2008, resulted in exactly 1,000 cases; in 2009, the number of cases reached a peak of 2,357 [7,8,9]. Research showed that the primary source of infection for humans was the wave of abortions on dairy goat farms, and that people that lived near these farms (within 5 km) were primarily affected [10]. As a result, the incidence of Q fever in the Netherlands differed between regions *(Figure 1)*. In the first instance, Q fever was mainly a local problem of the Noord-Brabant province, which had a high density of large dairy goat farms. However, in 2009, an alarming increase in Q fever incidence was observed in adjacent provinces, including Utrecht and Limburg [8,11]. In 2009, the Dutch government decided to tackle the source by imposing various veterinary measures [8,12]. Furthermore, veterinarians, physicians, and the public were informed through targeted mailings, publications, and the news media. When a dairy goat or dairy sheep farm tested positive for Coxiella burnetii, all inhabitants living within a radius of 5 km of the farm received a letter to inform them of the presence of a Q fever-positive farm in their proximity. In 2011, patients with specific cardiovascular conditions and patients with aortic aneurysms or vascular prostheses that lived in high-risk areas were offered Q fever vaccinations [13]. These comprehensive measures have led to a significant decrease in the incidence of human cases (504 in 2010; 81 in 2011; 66 in 2012) [7].

Surveillance of public perceptions and behavioural responses during infectious disease outbreaks can provide useful information for designing health risk communications that achieve successful changes in public behaviour [14,15]. Studies on public perceptions and behavioural responses have been conducted during outbreaks of other zoonotic infections, including severe acute respiratory syndrome (SARS) and avian influenza [16-23]. However, studies on public perceptions and behaviors during Q fever outbreaks have been limited, and they were mainly directed at specific risk groups [13,24,25]. The aim of the present study was to identify trends over time (2009, 2010, and 2012) and regional differences in public perceptions and behavioural responses among inhabitants of three regions in the Netherlands with different incidences of human Q fever.

Methods

Timing of the three surveys

The first survey took place from 13 August to 1 September, 2009. This followed a sharp increase in the incidence of human cases in spring 2009, primarily in the province of Noord-Brabant (as in 2007 and 2008), but it had also spread geographically to adjacent provinces *(Figure 1)*. In late 2009 and early 2010, media attention markedly increased, and drastic veterinary measures were implemented. The second survey took place from 1 to 12 April 2010. This followed the period from January to May 2010, when 208 human cases were identified; this was lower than the number identified in the same period in 2009 [12]. The third survey took place from 2 to 17 April 2012, when the incidence had largely dropped off (66 cases in 2012) [7].

Participants

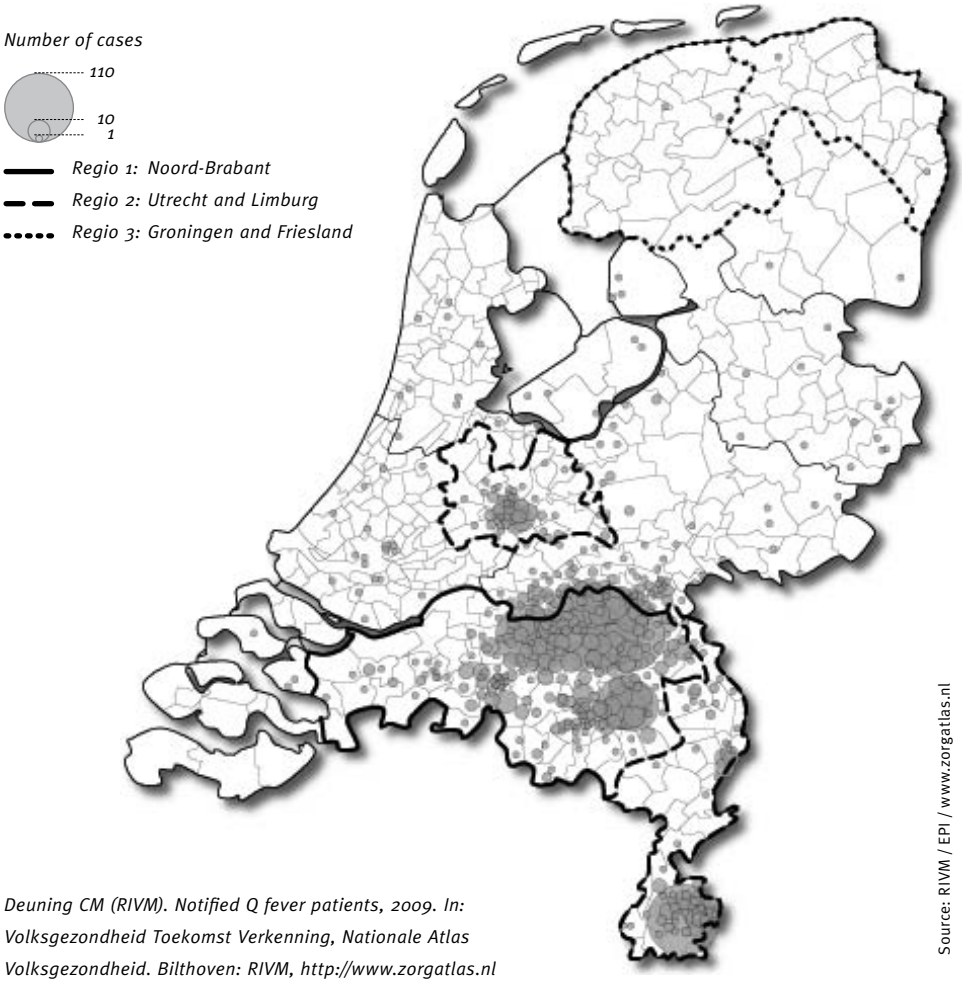
The survey was conducted through an internet panel (the Flycatcher panel; www.flycatcher.eu), which retains national list of volunteers with the distribution of demographic variables (gender, age, region, and level of education) comparable to the general Dutch population. These volunteers can be invited to participate in online surveys. The Flycatcher panel meets high quality requirements and is ISO-certified. Panel members of three regions with different incidences of Q fever were invited to participate in this study. The regions included Noord-Brabant, which had the highest incidence of human Q fever, and Utrecht and Limburg, where Q fever had been more recently introduced. Two other provinces with low incidences of human Q fever, Groningen and Friesland, served as control regions *(Figure 1)*. At three different time points, the participants completed an online survey. In the first survey, independent, random samples were selected for each geographical region; we invited a total of 2511 panel members (aged ≥18 years; about 800 per region). All respondents to the first survey were invited to participate in the second and third surveys. Sampled panel members were sent an email with an internet link. The surveys were available online for 5 to 10 days; during that time, panel members were required to respond. Upon completion of each survey, panel members received 1.50 Euro in credits, which could be exchanged for gift vouchers through the Flycatcher website.

This general, internet-based survey conducted with healthy volunteers from the general population did not require formal, medical ethical approval, according to Dutch law [26].

Online questionnaire

The questionnaires were based on questionnaires used in similar studies on SARS, avian influenza, and Influenza A (H1N1) [18,21,22,27], with some modifications. The questions were based on an integrated model designed to explain health behaviour. Constructs were used from the Protection Motivation Theory [28] and the Health Belief Model [29]; they included perceived severity and vulnerability, feelings of anxiety, perceived efficacy of preventive measures, a persons' ability (self-efficacy) and intention to take measures, and actual preventive behaviour. Participants were asked about eight (hypothetical) preventive measures against Q fever. Knowledge was examined with 7 true/false statements. The questionnaire concluded with items on the amount of information received on Q fever, attention paid to the information, and the reliability and sufficiency of governmental information. The questionnaires were similar across the three survey rounds (Additional file 1).

Figure 1 Notified patients with Q fever in 2009 (N=2,357)



Deuning CM (RIVM). Notified Q fever patients, 2009. In: Volksgezondheid Toekomst Verkenning, Nationale Atlas Volksgezondheid. Bilthoven: RIVM, http://www.zorgatlas.nl Zorgatlas\Gezondheid en ziekte\Ziekten en aandoeningen\ Infectieziekten, 18 december 2009.

Source: RIVM / EPI / www.zorgatlas.nl

Analysis

Data analysis was performed with SPSS for Windows, release 19.0. For all constructs with 3 or more items, Cronbach's alpha was calculated (range 0.6 to 0.8). Therefore, for each construct, a summary score was calculated by summing the individual item scores and dividing by the number of items. For assessing knowledge, a summary score was created based on the number of correct answers (range 0-7). Paired t-tests (for comparing means) and McNemar tests (for comparing percentages) were used to analyse time trends between the baseline and first follow-up survey, and between the first and second follow-up surveys. Overall significant trends over time for the 3 regions are shown in the tables. Deviant trends for a specific region are described in the text.

Univariate logistic regressions were used to assess confounding factors. Comparisons of regional public perceptions and behavioural responses were analysed with ANOVAs and adjusted for the confounders; a p-value ‹0.05 was considered statistically significant. For each outcome variable, corrected regional means were calculated based on the results from the ANOVA model.

Results

In August 2009, 2511 panel members were invited to participate. Of these, 64% (n=1609) responded (baseline study). In the first follow-up survey, all 1609 respondents from the baseline study were invited, and 79% (n=1263) responded. For the second follow-up survey, 1343 members of the 1609 respondents from the baseline study were invited, and 77% (n=1032) responded. A total of 1347 respondents completed at least 1 follow-up survey and were included in the analyses. Of these, 932 completed both follow-up surveys. Significant differences were observed in the sex, age, education, employment, and marital status of participants in different regions *(Table 1)*. Univariate logistic regression analyses showed that sex, age, education, and employment status were statistically significant determinants (p‹0.05) in the majority of outcome variables, but not marital status.

Trends over time (2009, 2010, 2012)
Public knowledge regarding Q fever increased significantly between 2009 and 2010, but decreased between 2010 and 2012 *(Table 2)*. In 2009, 33% of respondents answered 4 or more out of 7 knowledge items correctly (59% in 2010; 49% in 2012).

Perceived severity increased over time from 2009 to 2010, and from 2010 to 2012. Perceived severity of the disease was rather high; the majority of respondents agreed that "Q fever is a severe disease" (57%; 73%; 78%) and "Q fever is very harmful for my health" (53%; 63%; 67%). Also, the consequence of getting Q fever in the coming year was perceived as (very) severe among the majority of the respondents (57%; 70%; 77%).

The perceived personal susceptibility to Q fever remained stable over time from 2009 to 2010 and from 2010 to 2012. The perceived chance of getting infected in the coming year remained stable between 2009 and 2010, but then decreased between 2010 and 2012. Perceived vulnerability was rather low; a small minority of respondents perceived that they were quite/very susceptible (11%; 14%; 14%), and few perceived the chance of getting infected in the coming year as (very) likely (2%; 3%; 1%).

Perceived anxiety increased over time from 2009 to 2010, but decreased between 2010 and 2012. Perceived anxiety was low; a small minority of respondents worried about Q fever (5%; 8%; 6%), feared Q fever (3%; 5%; 4%), or thought about Q fever (very) often (1%; 1%; 1%).

From 2009 to 2010 and from 2010 to 2012, an increase was observed in the overall perceived efficacy of measures for preventing Q fever. However, between 2009 and 2010, decreasing trends were observed in the perceived efficacy of practicing better hygiene,

Table 1 Demographic characteristics of respondents in each region (Survey 1, August 2009)

Characteristics	Region 1: high incidence region[a] (n=459)	Region 2: medium incidence region[b] (n=491)	Region 3: low incidence region[c] (n=397)	Total (n=1347)	*p*-Value
Sex					
Male	52%	53%	35%	47%	
Female	48%	47%	65%	53%	‹0.001
Age					
18-30 years	14%	13%	26%	17%	
30-50 years	38%	43%	44%	42%	
Above 50 years	48%	44%	30%	41%	‹0.001
Ethnicity[d]					
Native Dutch	91%	91%	93%	92%	
Immigrant	9%	9%	7%	9%	ns
Education[e]					
Low	31%	34%	16%	28%	
Intermediate	40%	35%	45%	40%	
High	30%	31%	39%	33%	‹0.001
Employment status					
Employed	61%	62%	69%	64%	
Unemployed/ Retired	39%	38%	31%	36%	0.04
Marital status					
Single	17%	19%	25%	20%	
Married/ Cohabitating	80%	72%	69%	74%	
Divorced/ Widowed	4%	9%	5%	6%	‹0.001
Children ‹ 18 years in household					
Yes	34%	37%	40%	37%	
No	66%	63%	60%	63%	ns

[a] *Region 1 = Noord-Brabant – high incidence region;*

[b] *Region 2 = Utrecht & Limburg – intermediate incidence region;*

[c] *Region 3 = Groningen & Friesland – low incidence region;*

[d] *immigrant = born abroad or at least one parent born abroad;*

[e] *low educational level (i.e. primary education, lower general/vocational education or less);*
intermediate educational level (i.e. secondary general or vocational education);
high educational level (i.e. higher professional education or university);

ns = not significant. Chi² test was used to test demographic differences between regions.

Table 2. Trends over time in public perceptions and behaviors regarding Q fever in the Netherlands (2009, 2010, and 2012)

	Survey 1. August 2009 - baseline - (n=1347)		
	high score (%)[b]	mean	
Knowlegde			
Summary score – Chronbach's alpha 0.6	33	2.73	
Perceived severity [scale 1-5]			
1. "Q fever is a severe disease"	57	3.53	
2. "Q fever is very harmful for my health"	53	3.45	
3. Severity of getting Q fever coming year	57	3.67	
Summary score – Chronbach's alpha 0.7	--	3.55	
Perceived vulnerability [scale 1-5]			
1. Perceived susceptibility for oneself	11	2.63	
2. Perceived chance of getting infected coming year	2	2.22	
Perceived anxiety [scale 1-5]			
1. Worried about Q fever	5	2.17	
2. Fear for Q fever	3	2.11	
3. Thinking of Q fever	1	1.74	
Summary score – Chronbach's alpha 0.8	--	2.01	
Perceived efficacy [scale 1-5]			
1. Practice better hygiene	60	3.57	
2. Avoid Q fever affected regions	64	3.64	
3. Avoid contact with goats and sheep	81	4.13	
4. Do not use raw dairy products	57	3.57	
5. Wear face mask	24	2.65	
6. Move to place without Q fever	17	2.21	
7. Seek medical consultation with onset of symptoms	59	3.57	
8. Take antibiotics	34	3.01	
Summary score – Chronbach's alpha 0.7	--	3.29	
Perceived self-efficacy[d] [scale 1-5]			
1. Practice better hygiene	88	4.32	
2. Avoid Q fever affected regions	65	3.72	
3. Avoid contact with goats and sheep	83	4.26	
4. Do not use raw dairy products	71	3.94	
5. Wear face mask	40	3.15	
6. Move to place without Q fever	9	1.86	
7. Seek medical consultation with onset of symptoms	81	4.20	
8. Take antibiotics	73	3.98	
Summary score – Chronbach's alpha 0.8	--	3.68	
Intention[d] [scale 1-5]			
1. Practice better hygiene	86	4.33	
2. Avoid Q fever affected regions	70	3.86	
3. Avoid contact with goats and sheep	84	4.29	
4. Do not use raw dairy products	70	3.97	

	Survey 2. April 2010 - first follow-up - (n=1249)		Survey 3. April 2012 - second follow-up - (n=1030)[a]		Trends over time	
	high score (%)[b]	mean	high score (%)[b]	mean	Survey 1 versus 2 *p*-value[c]	Survey 2 versus 3 *p*-value[c]
	59	3.80	49	3.42	<0.001 (+)	<0.001 (-)
	73	3.79	78	3.89	<0.001 (+)	0.04 (+)
	63	3.65	67	3.73	<0.001 (+)	ns
	70	3.94	77	4.08	<0.001 (+)	<0.001 (+)
	--	3.79	--	3.90	<0.001 (+)	<0.001 (+)
	14	2.67	14	2.67	ns	ns
	3	2.20	1	2.03	ns	<0.001 (-)
	8	2.36	6	2.16	<0.001 (+)	<0.001 (-)
	5	2.23	4	2.12	<0.001 (+)	<0.001 (-)
	1	1.98	1	1.66	<0.001 (+)	<0.001 (-)
	--	2.19	--	1.98	<0.001 (+)	<0.001 (-)
	50	3.31	51	3.34	<0.001 (-)	ns
	75	3.92	80	4.10	<0.001 (+)	<0.001 (+)
	85	4.25	84	4.28	<0.001 (+)	ns
	60	3.65	66	3.84	0.04 (+)	<0.001 (+)
	30	2.85	45	3.29	<0.001 (+)	<0.001 (+)
	31	2.61	42	3.14	<0.001 (+)	<0.001 (+)
	55	3.46	51	3.42	<0.001 (-)	ns
	32	2.93	36	3.11	0.047 (-)	<0.001 (+)
	--	3.37	--	3.56	<0.001 (+)	<0.001 (+)
	84	4.22	82	4.21	<0.001 (-)	ns
	67	3.77	66	3.77	ns	ns
	85	4.26	83	4.22	ns	ns
	71	3.95	70	3.92	ns	ns
	40	3.08	42	3.15	0.04 (-)	ns
	12	1.99	13	2.10	0.001 (+)	0.005 (+)
	76	4.05	75	4.03	<0.001 (-)	ns
	67	3.81	71	3.90	<0.001 (-)	ns
	--	3.64	--	3.66	0.02 (-)	ns
	81	4.17	80	4.15	<0.001 (-)	ns
	69	3.82	72	3.93	ns	0.01 (+)
	83	4.24	82	4.22	0.03 (-)	ns
	70	3.93	71	3.95	ns	ns

Table 2. Trends over time in public perceptions and behaviors regarding Q fever in the Netherlands (2009, 2010, and 2012) *(continued)*

	Survey 1. August 2009 - baseline - (n=1347)	
	high score (%)[b]	mean
5. Wear face mask	40	3.10
6. Move to place without Q fever	8	1.79
7. Seek medical consultation with onset of symptoms	79	4.17
8. Take antibiotics	68	3.90
Summary score – Chronbach's alpha 0.8	--	3.68

ns = not statistically significant;

a 932 respondents participated in both follow-up surveys (331 of region 1; 350 of region 2; 251 of region 3);

b percentage of respondents who scored 4-5 (except for knowledge: percentage of respondents who answered 4 or more out of 7 items correctly);

seeking medical consultation with the onset of symptoms, and taking antibiotics. The measures with the highest perceived efficacies were avoiding contact with goats and sheep (81%; 85%; 84%) and avoiding Q fever-affected regions (64%; 75%; 80%). The measures with the lowest perceived efficacies were moving to a place without Q fever (17%; 31%; 42%) and wearing a face mask (24%; 30%; 45%).

Overall, perceived self-efficacy decreased between 2009 and 2010 and remained stable thereafter. However, the perceived self-efficacy of moving to a place without Q fever increased over the time period of the three surveys. Respondents felt most confident in practicing better hygiene (88%; 84%; 82%) and avoiding contact with goats and sheep (83%; 85%; 83%), and least confident in moving to a place without Q fever (9%; 12%; 13%) and wearing a face mask (40%; 40%; 42%).

Intentions to take preventive measures decreased between 2009 and 2010 and remained stable thereafter. However, between 2009 and 2010, the intention to move to a place without Q fever increased. Furthermore, between 2010 and 2012, intentions increased for some measures and decreased for others. Intentions were highest for practicing better hygiene (86%; 81%; 80%) and avoiding contact with goats and sheep (84%; 83%; 82%), and lowest for moving to a place without Q fever (8%; 11%; 11%) and wearing a face mask (40%; 36%; 39%).

The percentage of respondents that had taken one or more measures for preventing Q fever increased significantly between 2009 and 2010, but decreased between 2010 and 2012 *(Figure 2)*. However, the percentage that practiced better hygiene remained stable between 2009 and 2010 (16%; 15%, p=0.3). The respondents most often reported avoiding contact with goats and sheep (13%; 23%; 16%) and practicing better hygiene (16%; 15%; 11%).

Between 2009 and 2010, increases were observed in the amount of information respondents received on Q fever, the amount of attention paid to this information, and the perceived sufficiency of governmental information (data not shown). Between 2010

	Survey 2. April 2010 - first follow-up - (n=1249)		Survey 3. April 2012 - second follow-up - (n=1030)[a]		Trends over time	
	high score (%)[b]	mean	high score (%)[b]	mean	Survey 1 versus 2 *p*-value [c]	Survey 2 versus 3 *p*-value [c]
	36	3.00	39	3.10	0.003 (-)	0.04 (+)
	11	1.92	11	2.04	<0.001 (+)	0.003 (+)
	73	3.98	68	3.89	<0.001 (-)	<0.001 (-)
	63	3.71	61	3.71	<0.001 (-)	ns
	--	3.60	--	3.62	<0.001 (-)	ns

c time trends based on p-values obtained using paired t-tests; '(+)' indicates a significant increase over time p<0.05; '(-)' indicates a significant decrease over time p<0.05.

d respondents were asked to imagine that governmental health institutes would recommend the preventive measure;

and 2012, decreases were observed in the amount of information respondents received and the attention paid to information on Q fever. The perceived reliability of governmental information on Q fever was stable over time. A minority of respondents received (very) ample information (7%, 18%, 7%), and paid a high level of attention to it (6%, 12%, 3%). About one-third of respondents perceived that governmental information on Q fever was sufficient (22%, 34%, 30%), and almost half perceived that governmental information was reliable (42%, 44%, 48%).

In addition to the overall time trends, we analysed time trends within the 3 different Q fever incidence regions. Generally, the patterns remained the same, but some differences were observed. Although overall increasing trends were observed in the perceived severity and perceived efficacy of measures, these remained stable in the high incidence region (for resp. 2010-2012 and 2009-2010). Furthermore, although overall decreasing trends were observed in perceived self-efficacy and intentions to take measures between 2009 and 2010, these remained stable in the medium and low incidence regions. Finally, although the overall percentage of respondents that had taken one or more preventive measures first increased and later decreased, the percentage remained stable in the low incidence region.

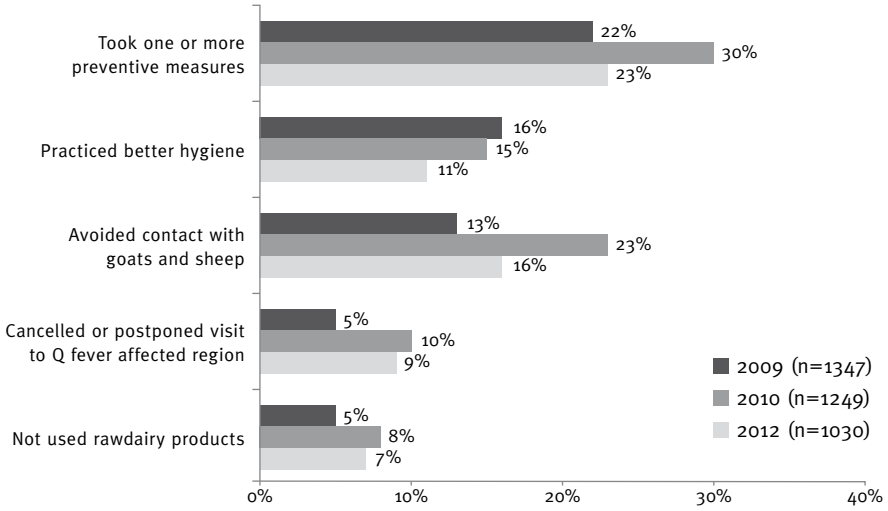
Regional differences

In 2009, 2010, and 2012, public knowledge regarding Q fever was highest in the high incidence region and lowest in the low incidence region *(Table 3)*.

Overall, there were no regional differences in the perceived severity of Q fever. In 2010, perceived consequences of getting Q fever in the coming year were considered most severe by respondents in the high incidence region and least severe by those in the low incidence region.

In 2009, the perceived personal susceptibility was highest in the high incidence region and lowest in the low incidence region; also in 2012, the perceived personal susceptibility

Figure 2 Trends over time in behavioral measures for preventing Q fever (2009, 2010, and 2012)



was lowest in the low incidence region. In 2010 and 2012, the perceived risk of sustaining an infection in the coming year was highest among respondents in the high incidence region and lowest among respondents in the low incidence region.

In all three surveys, perceived anxiety was highest in the high incidence region and lowest in the low incidence region. However, no regional differences were observed in the fear of Q fever in 2009 and 2010.

Regional differences were observed in the overall perceived efficacy of measures only in 2009; the perceived efficacy was highest among respondents in the high incidence region and lowest among respondents in the medium incidence region. For the specific measures, regional differences were observed in avoiding contact with goats and sheep (highest in the high incidence region; 2009) and moving to a place without Q fever (highest in the low incidence region; 2009 and 2012).

No regional differences were observed in the overall perceived self-efficacy in 2009, but there were differences in perceptions self-efficacy of specific measures. The perceived self-efficacies of avoiding Q fever-affected regions and moving to a place without Q fever were highest in the low incidence region, and avoiding contact with goats and sheep was highest in the high incidence region. In 2010 and 2012, the overall perceived self-efficacy was highest in the low incidence region. In particular, perceived self-efficacies of avoiding regions with Q fever, wearing a face mask, and moving to a place without Q fever were highest in the low incidence region in 2010 and 2012, and the self-efficacy of not using raw dairy products only in 2012.

No regional differences in the overall intention to take measures were observed over the three surveys. However, for some specific measures, regional differences were observed.

In the high incidence region, respondents had the highest intentions of practicing better hygiene and avoiding contact with goats and sheep (2009); in the low incidence region, respondents had the highest intentions of avoiding Q fever-affected regions (2009, 2010), wearing a face mask (2010), and moving to a place without Q fever (all three surveys).

In all three surveys, respondents in the high incidence region most often took measures to prevent Q fever *(Figure 3)*. For example, they practiced better hygiene, avoided contact with goats and sheep, cancelled/postponed visits to Q fever-affected regions (2010), and did not use raw dairy products (2009).

Regional differences were observed in the reported amount of information received (all three surveys), in the amount of attention paid to that information (all three surveys), and in the perceived sufficiency of information provided by the government (2009). All amounts were highest among respondents in the high incidence region (data not shown). There were no regional differences in the perceived reliability of governmental information on Q fever.

Discussion

Between 2009 and 2010, we found increases in the public knowledge, perceived severity, anxiety, and perceived efficacy of measures related to Q fever in the Netherlands. In the same period, increases were also observed in actual behaviour, the amount of information received, the attention paid to the information, and the perceived sufficiency of government-provided information. These increasing trends coincided with marked increases in media attention to the Q fever epidemic in the Netherlands and in the drastic veterinary measures that were implemented in late 2009 and early 2010. Other studies also described an association between media coverage/the amount of information people received and the levels of public knowledge/risk perception [22,30]. Apparently, in April 2010 (when the first follow-up survey took place), the public was not well-informed on the reduced number of human cases during the spring of 2010. Perhaps public risk perception and preventive behaviour had not yet decreased at that time, due to the increase number of fatal cases reported (7 in 2009; 11 in 2010) and the recent implementation of veterinary measures. In 2011 and 2012, the number of new human Q fever cases decreased further, largely as a result of the implemented veterinary measures [12]. Furthermore, at that time, media attention had decreased regarding the Q fever epidemic in the Netherlands. This may have led to the decreases (between 2010 and 2012) in public knowledge, perceived anxiety, preventive behaviour, amount of information received, and attention paid to the information on Q fever.

Respondents in the high incidence region exhibited the highest levels of public knowledge, perceived anxiety, preventive behaviour, amount of information received, and attention paid to the information. This was most likely due to the facts that this region had a high density of large dairy goat farms, had the first community outbreak of Q fever, and had the most human Q fever cases. Also, the local media in that region focused more attention on the Q fever epidemic.

Table 3 Regional differences in public perceptions and behaviors regarding Q fever in the Netherlands (high, medium, and low incidence regions)

	Survey 1 (August 2009) - baseline -			
	Region 1: high incidence (n=459) mean[b]	Region 2: medium incidence (n=491) mean[b]	Region 3: low incidence (n=397) mean[b]	*p*-value[a]
Knowlegde				
Summary score – Chronbach's alpha 0.6	2.99	2.73	2.45	‹0.001
Perceived severity				
1. "Q fever is a severe disease"	3.50	3.58	3.49	ns
2. "Q fever is very harmful for my health"	3.44	3.48	3.42	ns
3. Severity of getting Q fever coming year	3.68	3.68	3.65	ns
Summary score – Chronbach's alpha 0.7	3.54	3.58	3.52	ns
Perceived vulnerability				
1. Perceived susceptibility for oneself	2.73	2.60	2.58	0.003
2. Perceived chance of getting infected coming year	2.73	2.67	2.60	ns
Perceived anxiety [scale 1-5]				
1. Worried about Q fever	2.25	2.18	2.10	0.02
2. Fear for Q fever	2.16	2.09	2.07	ns
3. Thinking of Q fever	1.91	1.68	1.60	‹0.001
Summary score – Chronbach's alpha 0.8	2.11	1.98	1.92	‹0.001
Perceived efficacy [scale 1-5]				
1. Practice better hygiene	3.63	3.50	3.58	ns
2. Avoid Q fever affected regions	3.63	3.63	3.66	ns
3. Avoid contact with goats and sheep	4.22	4.17	3.98	‹0.001
4. Do not use raw dairy products	3.61	3.49	3.64	ns
5. Wear face mask	2.68	2.57	2.73	ns
6. Move to place without Q fever	2.26	2.03	2.37	‹0.001
7. Seek medical consultation with onset of symptoms	3.62	3.58	3.50	ns
8. Take antibiotics	3.07	2.95	3.01	ns
Summary score – Chronbach's alpha 0.7	3.34	3.24	3.31	0.03
Perceived self-efficacy[c] [scale 1-5]				
1. Practice better hygiene	4.38	4.31	4.27	ns
2. Avoid Q fever affected regions	3.57	3.73	3.90	‹0.001
3. Avoid contact with goats and sheep	4.35	4.22	4.21	0.04
4. Do not use raw dairy products	3.99	3.90	3.95	ns
5. Wear face mask	3.13	3.07	3.27	ns
6. Move to place without Q fever	1.74	1.76	2.13	‹0.001
7. Seek medical consultation with onset of symptoms	4.24	4.20	4.16	ns
8. Take antibiotics	4.04	3.96	3.95	ns
Summary score – Chronbach's alpha 0.8	3.68	3.64	3.73	ns
Intention[c] [scale 1-5]				
1. Practice better hygiene	4.39	4.32	4.25	0.046

	Survey 2 (April 2010) - first follow-up -				Survey 3 (April 2012) - second follow-up -			
	Region 1: high incidence (n=430) mean[b]	Region 2: medium incidence (n=456) mean[b]	Region 3: low incidence (n=363) mean[b]	*p*-value[a]	Region 1: high incidence (n=354) mean[b]	Region 2: medium incidence (n=375) mean[b]	Region 3: low incidence (n=277) mean[b]	*p*-value[a]
	4.02	3.67	3.68	0.001	3.55	3.44	3.22	0.04
	3.75	3.81	3.80	ns	3.90	3.90	3.86	ns
	3.64	3.65	3.66	ns	3.69	3.76	3.75	ns
	4.02	3.95	3.84	0.03	4.11	4.12	4.02	ns
	3.80	3.81	3.77	ns	3.90	3.93	3.88	ns
	2.73	2.67	2.61	ns	2.72	2.72	2.54	0.003
	2.29	2.19	2.11	0.02	2.12	2.10	1.87	‹0.001
	2.47	2.31	2.30	0.004	2.25	2.18	2.06	0.02
	2.29	2.22	2.18	ns	2.20	2.14	2.03	0.03
	2.12	1.94	1.86	‹0.001	1.76	1.67	1.54	‹0.001
	2.29	2.15	2.12	‹0.001	2.07	2.00	1.88	0.001
	3.31	3.28	3.36	ns	3.27	3.35	3.41	ns
	3.90	3.91	3.96	ns	4.04	4.11	4.15	ns
	4.32	4.25	4.18	ns	4.29	4.28	4.27	ns
	3.61	3.65	3.70	ns	3.81	3.87	3.86	ns
	2.83	2.79	2.95	ns	3.22	3.27	3.39	ns
	2.69	2.50	2.66	ns	3.19	3.01	3.24	0.04
	3.53	3.39	3.46	ns	3.46	3.42	3.37	ns
	2.97	2.87	2.96	ns	3.11	3.11	3.13	ns
	3.39	3.34	3.40	ns	3.55	3.55	3.60	ns
	4.18	4.26	4.19	ns	4.25	4.18	4.20	ns
	3.55	3.78	4.02	‹0.001	3.58	3.81	3.99	‹0.001
	4.28	4.25	4.25	ns	4.23	4.19	4.26	ns
	3.94	3.90	4.03	ns	3.84	3.94	4.05	0.03
	3.02	3.00	3.27	0.003	3.07	3.12	3.31	0.04
	1.90	1.88	2.23	‹0.001	2.00	2.04	2.28	0.006
	4.06	4.01	4.07	ns	4.03	4.03	4.03	ns
	3.83	3.80	3.81	ns	3.91	3.87	3.92	ns
	3.60	3.61	3.73	0.008	3.62	3.65	3.76	0.04
	4.20	4.22	4.06	0.048	4.18	4.17	4.09	ns

Table 3 Regional differences in public perceptions and behaviors regarding Q fever in the Netherlands (high, medium, and low incidence regions) *(continued)*

	Survey 1 (August 2009) - baseline -			
	Region 1: high incidence (n=459) mean[b]	Region 2: medium incidence (n=491) mean[b]	Region 3: low incidence (n=397) mean[b]	*p*-value[a]
2. Avoid Q fever affected regions	3.77	3.87	3.97	0.04
3. Avoid contact with goats and sheep	4.39	4.30	4.19	0.01
4. Do not use raw dairy products	4.06	3.91	3.96	ns
5. Wear face mask	3.14	3.03	3.14	ns
6. Move to place without Q fever	1.73	1.70	1.98	‹0.001
7. Seek medical consultation with onset of symptoms	4.23	4.15	4.12	ns
8. Take antibiotics	3.95	3.88	3.87	ns
Summary score – Chronbach's alpha 0.8	3.71	3.65	3.69	ns

ns = not statistically significant;

a p-value obtained using ANOVA with sex, age, education, and employment status as confounders;

b means are corrected for differences in sex, age, education, and employment status;

c respondents were asked to imagine that governmental health institutes would recommend the preventive measure.

Surprisingly, the perceived vulnerability and perceived anxiety were rather low, even in the high incidence region, during the peak of the epidemic. This was remarkable, because there was a high risk of becoming infected in this region; around 75% of the total 2,357 cases in 2009 had occurred in this region. This suggested that the public had underestimated the risk of contracting Q fever. This "optimistic bias" could have had an adverse effect on risk perception and public compliance; this has also been described in other studies [27,31,32]. Furthermore, voluntary exposure to unhealthy conditions (like smoking or unsafe sex) was shown to be a mediator of risk acceptance [33]. In the case of Q fever, exposure is (in the majority of cases) involuntary; therefore, one would expect higher levels of perceived vulnerability and perceived anxiety, particularly in the high incidence region, where many people live within 5 km of an affected farm. It is important for the public to have an appropriate level of perceived vulnerability, because those that perceive themselves at risk are more likely to comply with government-advised preventive measures [16,18,34].

If worn properly, face masks are an effective intervention strategy in controlling an outbreak [35]. Studies conducted in Asia during outbreaks of SARS and avian influenza reported rather high levels of face mask use among the general public [16,20]. However, we found low levels of perceived (self-)efficacy and intention to wear face mask. Possible explanations are the fact that wearing a face mask has many practical barriers and appears to be associated with negative feelings, like disease victimization, and stigmatization.

A clear strength of this study was that data collection took place during an actual epidemic situation, in contrast to other studies, which used scenarios based on hypothetical

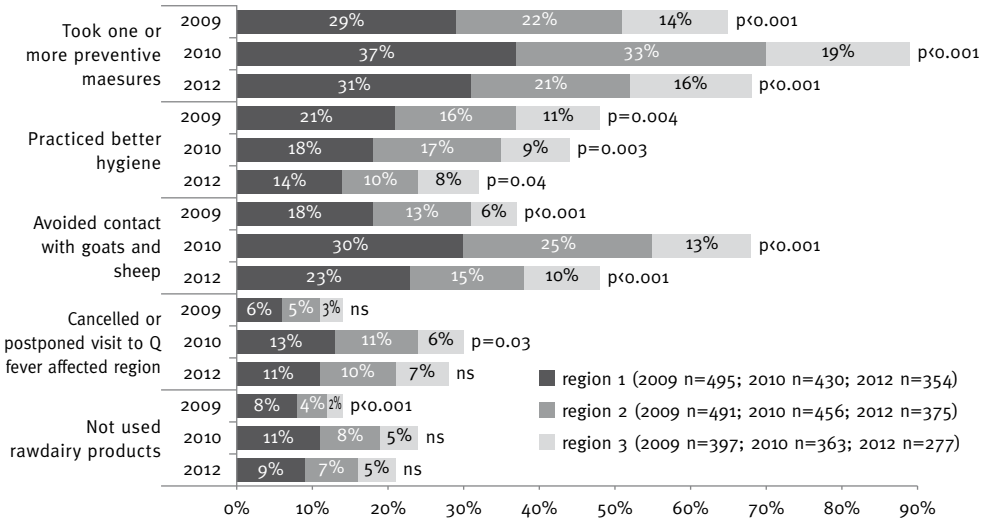
	Survey 2 (April 2010) - first follow-up -				Survey 3 (April 2012) - second follow-up -			
	Region 1: high incidence (n=430) mean[b]	Region 2: medium incidence (n=456) mean[b]	Region 3: low incidence (n=363) mean[b]	*p*-value[a]	Region 1: high incidence (n=354) mean[b]	Region 2: medium incidence (n=375) mean[b]	Region 3: low incidence (n=277) mean[b]	*p*-value[a]
	3.69	3.85	3.95	0.006	3.82	4.02	4.00	0.02
	4.29	4.23	4.20	ns	4.25	4.25	4.18	ns
	3.95	3.87	3.99	ns	3.94	4.00	3.94	ns
	2.92	2.94	3.17	0.01	3.06	3.12	3.17	ns
	1.80	1.87	2.12	<0.001	1.96	1.98	2.20	0.02
	4.01	3.99	3.95	ns	3.92	3.89	3.85	ns
	3.73	3.68	3.73	ns	3.82	3.68	3.67	ns
	3.57	3.58	3.64	ns	3.62	3.64	3.64	ns

situations. Another strength was that this study consisted of three repeated survey rounds; this enabled the analysis of trends over time. Moreover, we followed-up individuals; thus, the differences between survey rounds represented real trends over time and were not due to differences between study populations [36]. Furthermore, we used an online questionnaire, which created less of a social desirability bias than personal telephone interviews.

This study also had some limitations. First, the surveys took place in different months of the year (August in 2009 and April in 2010 and 2012). Although cases of Q fever can occur at any time of the year, most cases reported the onset of illness during the spring and early summer months, with peaks in April and May [8,12]. Our first survey took place during the summer, when the number of new human Q fever cases decreased. The second and third surveys took place during the spring, when the number of Q fever cases had increased. Thus, survey timing may have had some influence on public perceptions and behaviours. Second, our study population comprised inhabitants of three regions. Therefore, the results may not be generalisable to the whole country. Third, the fact that it was a follow-up study may have influenced participating respondents; after the first survey, they might have become more aware of Q fever in the Netherlands, and therefore, they might have paid more attention to information on Q fever in the media.

Our study had several implications for health authorities. First, when levels of knowledge, public perceptions, and/or behavioural responses are generally low, providing the public with more information through the media is expected to increase these factors. During future outbreaks of (zoonotic) infectious diseases, it will be important to provide the public with accurate and up-to-date information on the risk of becoming infected to instil a realistic sense of vulnerability. This should be given in addition to information about the severity of the disease, information on the efficacy of measures, and instructions for minimising infection risk with appropriate, feasible measures. Second, health communicators should

Figure 3 Regional differences in behavioral measures for preventing Q fever (high, medium, and low incidence regions)



ns = not statistically significant. Note that p-values were obtained using ANOVA with sex, age, education, and employment status as confounders; percentages are raw percentages.

take the public's perceptions into account when formulating messages about the prevention of zoonotic infections; these messages should be adapted to regional circumstances. Therefore, surveillance of public perceptions and behavioural responses during outbreaks of infectious diseases is important. Furthermore, involving the public in risk communication or the decision-making process regarding the implementation of public preventive measures could have added value, because the public can provide important information, particularly about the (practical) feasibility of specific preventive measures. This is consistent with a previous evaluation report of the Q fever epidemic in the Netherlands, which stated that "the public should be more involved in the dilemmas of the government" [37].

Conclusion

Overall, the trends over time and the regional differences in public perceptions and behaviours regarding Q fever appeared to parallel the trends in the number of new human Q fever cases in the different epidemiological regions in 2009, 2010, and 2012, and the amount of media attention on Q fever in the Netherlands during those years. However, the low levels of perceived vulnerability and perceived anxiety were remarkable, particularly in the high incidence region, with three-quarters of the total cases in 2009. During future outbreaks of (zoonotic) infectious diseases, it is therefore important to provide the public accurate information on the risk of becoming infected to instil a realistic sense of vulnerability. Furthermore, information should be adapted to regional circumstances. New research could focus on searching for the most effective methods (e.g., personalising risk) for providing this information during future outbreaks of infectious diseases.

Authors' contributions
All authors contributed to the study design. MB, HV, DB, and CW played a primary role in the data collection. Data analysis was performed by MB and HV. MB and HV wrote the first draft of the manuscript; DB, CW, and JHR critiqued the manuscript and contributed to further drafts. HV is the guarantor. All authors read and approved the final manuscript.

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Competing interest: none declared.
Data sharing: data are available on request from MB *m.bults@rotterdam.nl*

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CHAPTER 7

Why did patients with cardiovascular disease in the Netherlands accept Q fever vaccination?

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Abstract

This study examines patient's reasons for accepting Q fever vaccination, including risk perception, feelings of doubt, social influence, information-seeking behavior, preventive measures taken, and perceptions regarding received information and governmental action. Data was obtained from exit interviews conducted after Q fever vaccination, between January and April 2011. A total of 413 patients with specific cardiovascular conditions in the Netherlands participated in exit interviews; 70% were older than 60 years. Most reported reasons for accepting Q fever vaccination were: "I am at an increased risk for developing (chronic) Q fever" (69%) and "my general practitioner recommends Q fever vaccination for me" (34%). The majority (86%) reported a high perceived severity of Q fever, and only 6% felt vulnerable to Q fever after vaccination. One-third had doubts about getting vaccinated, primarily related to fears of side effects and practical barriers. Fifty-two percent solicited advice from their social networks; of these, 67% reported influence on their vaccination decision. General practitioners and family were the most reported sources of advice. Thirty percent actively sought information about Q fever vaccination. Twenty-two percent of all respondents had taken other preventive measures, such as avoiding contact with goats and sheep (74%), and cancelling or postponing visits to Q fever-affected areas (36%). Almost one-half of all respondents reported negative feelings regarding governmental action to control Q fever. Significant differences were observed regarding feelings of doubt, information-seeking behavior, perceived vulnerability, preventive measures taken, and perceptions regarding received information and governmental action regarding gender, age, educational level, and/or employment status. Vaccination decision-making may differ among socio-demographic subgroups. When preparing future vaccination campaigns, it is important to obtain greater insight into these differences and take these aspects into account in risk communication strategies by tailoring information to specific target groups.

Keywords
Q fever vaccination, vaccination acceptance, major motives, risk perception, feelings of doubt, social influence, information-seeking behavior.

Introduction

Q fever is a zoonosis caused by the bacterium Coxiella burnetii. Although the primary reservoirs of the bacterium are farm animals, such as goats, sheep and cattle, the causative agent has also been isolated in many other animal species [1]. Infection in humans primarily occurs through the inhalation of contaminated dust. C. burnetii infection is asymptomatic in the majority of the cases; however, when symptoms do occur, an acute and a chronic form can be discerned [2,3]. Acute Q fever usually presents as an influenza-like illness, pneumonia, or hepatitis. Approximately 1%-5% of all Q fever cases may progress to a chronic infection, often leading to life-threatening endocarditis. Patients with heart valve disorders are at high risk of developing Q fever endocarditis [2,4,5]. Although Q fever is associated with significant morbidity, mortality is uncommon (1%-2% of all cases) [6].

Q fever has recently become a major public health problem in the Netherlands. In 2007, the first community outbreak of Q fever in the south of the Netherlands involved 168 cases [7,8]. The second wave (in 2008) resulted in 1000 cases, and in 2009 the number of cases reached a peak of 2357 [8,9,10]. Because most human cases in the Netherlands were linked to abortion waves on large dairy goat farms, interventions were primarily directed at these farms [11]. In 2009, the Dutch government decided to tackle the source by taking various veterinary measures, implementing a nationwide hygiene protocol, mandatory bulk milk monitoring on farms with more than 50 dairy goats or sheep, and a culling campaign for pregnant goats and sheep on infected farms [8]. These comprehensive measures have led to a significant reduction in the number of human cases, with 504 patients reported in 2010 [10].

In 2010, the Health Council of the Netherlands (HCN) advised the Minister of Health and Welfare regarding the vaccination of high-risk populations to reduce infections in humans [12]. The only vaccine against Q fever that is available for use in humans has been developed in Australia (Q-VAX®). Its efficacy and safety were only tested on a selected group of mainly healthy individuals with occupational exposure, such as abattoir workers [13-18]. Q-VAX® has not been licensed for use in the Netherlands. Nevertheless, the HCN considered the benefits of vaccination to outweigh possible risks, particularly for patients with specific cardiovascular conditions living in high-risk areas. The Dutch Minister of Health endorsed the advice of the HCN to vaccinate patients who had specific cardiovascular conditions, as well as patients with a known aortic aneurysm or vascular prosthesis living in high-risk areas in the south of the Netherlands. Vaccination was offered at one Municipal Public Health Service in the south of the Netherlands ('s Hertogenbosch) between 28 January and 20 April 2011. Because vaccination was contraindicated in persons who had been infected previously with C. burnetii, pre-vaccination screening (serological and skin test) was performed 7 days before vaccination. A total of 2688 patients were considered eligible by their general practitioner or specialist; of these, 1366 patients were actually vaccinated against Q fever.

Surveillance of perceptions and behavioral responses of the public during outbreaks of infectious diseases provides useful information for health risk communication and can contribute to successful changes in public behavior [19,20]. Few studies provide insight into the decision-making processes of specific target groups regarding Q fever preventive measures [21,22]. This study aimed to examine reasons for accepting Q fever vaccination,

risk perception, feelings of doubt, social influence, information-seeking behavior, preventive measures taken, and perceptions regarding received information and governmental action, among patients belonging to a high-risk group for complications due to Q fever.

Materials and methods

This study was conducted among patients with specific cardiovascular conditions who were targeted for Q fever vaccination [12]. Practical feasibility and available funds allowed for a sample size of 350 patients to be interviewed. Vaccination was offered between 28 January and 20 April 2011 at one Municipal Public Health Service in the south of the Netherlands ('s Hertogenbosch). Data were collected on 28 February; 5, 19, and 26 March; and 2 April 2011. Approximately 100 patients were vaccinated per day. All 500 patients who were vaccinated during the data collection days were invited to participate in the exit interview. Patients were approached for exit interviews by trained interviewers. The nature of this study involving voluntary participation of subjects in an exit-interview, does not require formal medical ethical approval according to the Dutch law [23].

Based on existing questionnaires for risk perception and precautionary behaviors of the public during the 2009 H1N1 pandemic and during the SARS and avian influenza outbreaks [24-26], a 33-item questionnaire was developed. The questionnaire was based on an integrated model to explain health behavior, including constructs from the Protection Motivation Theory [27] and the Health Belief Model [28]. Questions were aimed at demographic characteristics, reasons for accepting Q fever vaccination, risk perception of Q fever, feelings of doubt, social influence, information-seeking behavior, preventive measures taken, and perceptions regarding received information and governmental action. Similar questions regarding Influenza A(H1N1) vaccination were pretested by the general public by means of cognitive interviewing (a combination of thinking aloud and verbal probing techniques) and revised to enhance comprehensibility.

Data were entered via the electronic scanning of questionnaires. SPSS for Windows Release 17.0 (SPSS Inc., Chicago, IL, USA) was used to analyze the quantitative data from the exit interviews. The Chi-squared test was used to test statistical significance of group differences (gender, age, educational level, and employment status) regarding risk perception, feelings of doubt, social influence, information-seeking behavior, preventive measures taken, and perceptions regarding received information and governmental action. Additionally, to test interplay of group differences, multivariate regression analyses were performed for those outcome measures for which more than one demographic variable was significant in the univariate analyses (i.e. feelings of doubt, information seeking behavior, informed being a target group via general practitioner and local/regional newspapers, being satisfied about way of informing). P-values <0.05 were considered statistically significant.

Results

A total of 1366 patients were vaccinated against Q fever. Approximately 500 patients were approached; of these, 413 granted permission to be interviewed (61% men). The majority (70%) were older than 60 years; 24% were between 41 and 60 years; and 6% were 40 years or younger. Forty-nine percent had a lower education (i.e. primary education, lower general/vocational education, or less), 23% an intermediate education (i.e. secondary general/vocational education), and 29% had a higher educational level (i.e. higher professional education or university). Twenty-nine percent of all respondents were employed.

The most frequently reported reasons for accepting Q fever vaccination were: "I am at an increased risk for developing (chronic) Q fever" (69%); "my general practitioner recommends Q fever vaccination for me" (34%); and "Q fever can be severe (resulting in hospitalizations/deaths/chronic symptoms)" (14%) *(Figure 1)*. Other reasons were: "my specialist recommends Q fever vaccination for me" (7%); "I am very susceptible to infections" (6%); "I live in an affected area/an area with many sheep and goats" (6%); and "If I don't do it, I will regret it" (4%). Based on the results from the univariate regression analyses, "my general practitioner recommends Q fever vaccination for me" was more often reported as reason for Q fever vaccination acceptance by respondents aged 60 years or older ($p<0.001$) and lower educated ($p = 0.02$); and "I live in an affected area/an area with many sheep and goats" was more often reported by respondents with a higher educational level ($p = 0.04$; data not shown).

Eighty-six percent of all respondents agreed with the statements that "Q fever is a severe disease", and "Q fever is very harmful for my health"; 19% reported that they thought about Q fever regularly *(Table 1)*. Perceived severity of Q fever did not differ with regard to gender, age, educational level, or employment status. One-third of the respondents had doubts about being vaccinated against Q fever. Females ($p<0.001$), subjects aged 60 years or younger ($p = 0.007$), and employed respondents ($p = 0.02$) more often reported feelings of doubt about the vaccination decision. These doubts were mostly related to "fear of severe side effects (in the longer term)" (20%; 26/130); "fear of mild side effects (i.e. local adverse events and/or mild systemic symptoms)" (19%; 25/130); "practical barriers" (19%; 24/130), and "vaccine has not been thoroughly tested" (10%; 13/130) (data not shown). Approximately one-half of all respondents (52%) solicited advice from their social networks regarding Q fever vaccination; of these, 67% reported that this advice influenced their vaccination decision (no differences were observed with regard to socio-demographic groups). The most frequently reported sources for advice were general practitioners (60%; 128/215), family (32%; 68/215), specialists (13%; 28/215), and friends (13%; 27/215) (data not shown). Thirty percent of all respondents had actively sought information about Q fever vaccination. Respondents aged 60 years or younger ($p = 0.006$), those with a higher educational level ($p = 0.001$), and those employed ($p = 0.001$) more often sought information. After respondents had been vaccinated, 6% felt vulnerable to being diagnosed with Q fever within the next 12 months (no differences were observed with regard to socio-demographic groups); 9% experienced feelings of worry that they might be diagnosed with Q fever within the next 12 months. Women reported being worried more often than men ($p = 0.04$). Of all respondents, 22% took preventive measures in addition to getting vaccinated; of these, 74% (65/88)

Table 1 Factors related to Q fever vaccination acceptance among patients with specific cardiovascular conditions, by demographic characteristics (n = 413)

	Gender			Age		
	Male	Female	*p*-value	≤60 yrs	>60 yrs	*p*-value
1. Perceived severity						
Q fever is a severe disease						
Mostly/totally agree	88%	84%	ns	81%	88%	ns
Q fever is very harmful for my health						
Mostly/totally agree	88%	84%	ns	83%	88%	ns
How often do you think about Q fever?						
Sometimes/(very) often	16%	23%	ns	19%	18%	ns
2. Feelings of doubt						
Did you have doubts about getting vaccinated against Q fever?						
Some/many doubts	24%	44%	<0.001	41%	28%	0.007
3. Social influence						
Did you ask advice from other people about Q fever vaccination?						
Yes	52%	53%	ns	53%	52%	ns
***If yes;* Was this advice of influence on your decision to get vaccinated?**						
Probably/certainly	68%	68%	ns	66%	68%	ns
4. Information-seeking behavior						
Have you actively sought information about Q fever vaccination?						
Yes	28%	32%	ns	39%	25%	0.006
5. Perceived vulnerability, after vaccination						
Now you have been vaccinated, how likely is it that you will be diagnosed with Q fever in the next 12 months?						
Even/likely/very likely	6%	6%	ns	7%	6%	ns
Now you have been vaccinated, how worried are you to be diagnosed with Q fever in the next 12 months?						
A bit/(very) worried	7%	12%	0.04	11%	8%	ns
6. Preventive measures taken						
Took any preventive measures (other than vaccination)						
Yes	24%	17%	ns	23%	21%	ns

[†] *Lower educational level (i.e. primary education, lower general/vocational education or less);*

[‡] *intermediate educational level (i.e. secondary general/vocational education);*

[₮] *higher educational level (i.e. higher professional education or university);*

ns = not significant. P-values were derived using Chi-squared tests.

	Educational level				Employment status			Overall	
	Lower†	Intermediate‡	Higher¥	*p*-value	Employed	Unemployed /retired	*p*-value	%	n/ntot
	84%	88%	88%	ns	84%	87%	ns	86%	353/411
	88%	82%	86%	ns	86%	86%	ns	86%	352/408
	17%	21%	21%	ns	24%	17%	ns	19%	76/409
	30%	35%	34%	ns	40%	28%	0.02	32%	130/410
	47%	57%	57%	ns	56%	51%	ns	52%	215/412
	73%	58%	65%	ns	64%	68%	ns	67%	140/209
	22%	31%	42%	0.001	41%	25%	0.001	30%	120/407
	7%	5%	8%	ns	8%	6%	ns	6%	26/405
	9%	7%	10%	ns	9%	9%	ns	9%	36/408
	16%	21%	31%	0.007	27%	19%	ns	22%	88/409

Table 2 Perceptions regarding received information and governmental action among patients who accepted Q fever vaccination, by demographic characteristics (n = 413)

	Gender			Age		
	Male	Female	*p*-value	≤60 yrs	>60 yrs	*p*-value
1. Received information						
How were you informed about being a target group for Q fever vaccination?						
Via general practitioner	67%	71%	ns	60%	72%	0.01
Via local/regional newspapers	18%	13%	ns	20%	14%	ns
Via television/radio	8%	6%	ns	9%	7%	ns
Via specialist	5%	8%	ns	4%	7%	ns
Were you satisfied about the way you were informed about being a target group for Q fever vaccination?						
Satisfied/very satisfied	78%	79%	ns	77%	79%	ns
What is the amount of information you received about Q fever vaccination?						
Much/very much	39%	41%	ns	36%	41%	ns
Did you consider the information you received to be comprehensive/reliable?						
Comprehensive/very comprehensive	85%	89%	ns	90%	85%	ns
Reliable/very reliable	89%	91%	ns	86%	91%	ns
2. What are your dominant feelings, about action of the Dutch government to control Q fever?						
Negative feelings	53%	44%	ns	53%	48%	ns

[†] Lower educational level (i.e. primary education, lower general/vocational education or less);

[‡] intermediate educational level (i.e. secondary general/vocational education);

[₹] higher educational level (i.e. higher professional education or university);

ns = not significant. P-values were derived using Chi-squared tests.

avoided contact with goats and sheep, 36% (32/88) cancelled or postponed a visit to Q fever-affected areas, 13% (11/88) sought advice from their general practitioner, and 11% (10/88) took any other preventive measure (data not shown). Respondents with a higher education took preventive measures in addition to vaccination more often than respondents in other educational brackets (p = 0.007).

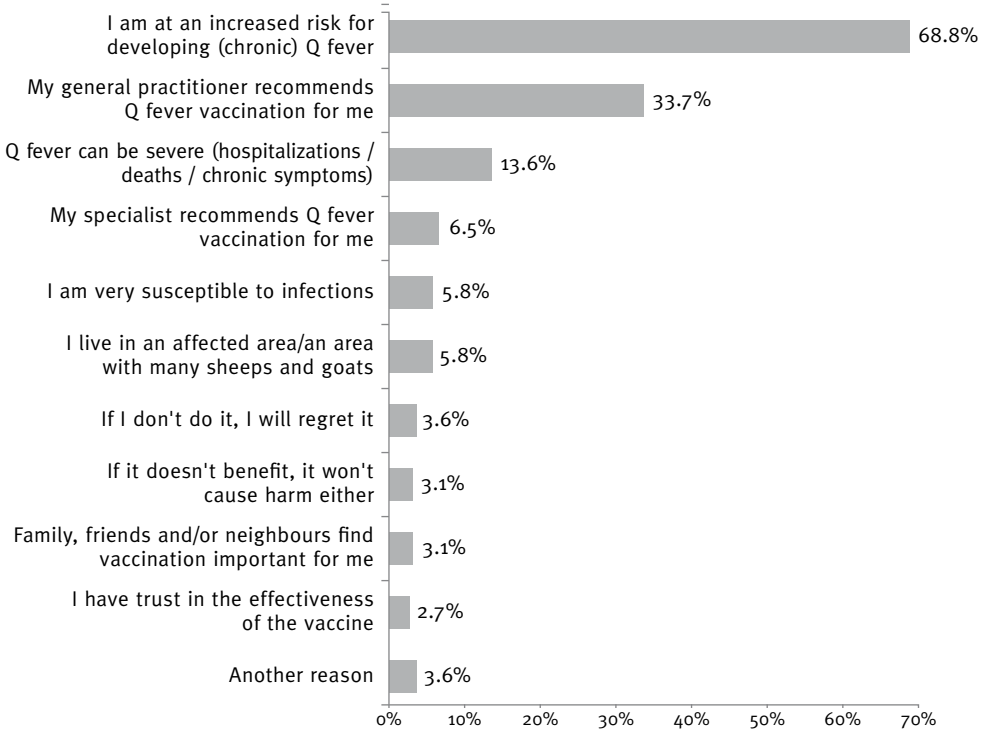
Sixty-eight percent of respondents were informed by their general practitioner that they were members of a target group for Q fever vaccination *(Table 2)*. Respondents who were older than 60 years (p = 0.01), lower educated (p < 0.001), or unemployed/retired (p = 0.004) were more often informed by their general practitioner. Sixteen percent were informed that they were members of a target group for Q fever vaccination via local/regional newspapers. Higher educated respondents (p = 0.002) and employed respondents (p = 0.04) were more often informed by local/regional newspapers. In addition, 8% were notified via radio and/or television, and 6% were notified by their specialist (no differences were observed with regard to socio-demographic groups). The majority (79%) was satisfied with how they were informed that they were members of a target group for Q fever vaccination. Lower educated respondents (p = 0.002) and unemployed/retired respondents (p = 0.03) were more often satisfied. Of all respondents,

	Educational level				Employment status			Overall	
	Lower†	Intermediate‡	Higher‡	*p*-value	Employed	Unemployed /retired	*p*-value	%	n/ntot
	75%	74%	53%	‹0.001	58%	72%	0.004	68%	282/413
	10%	16%	25%	0.002	22%	13%	0.04	16%	65/413
	8%	7%	9%	ns	9%	7%	ns	8%	31/413
	4%	8%	10%	ns	4%	7%	ns	6%	26/413
	83%	82%	67%	0.002	71%	81%	0.03	79%	314/400
	40%	46%	35%	ns	34%	42%	ns	40%	160/403
	83%	89%	89%	ns	90%	86%	ns	87%	326/377
	91%	89%	87%	ns	86%	92%	ns	90%	335/374
	44%	45%	64%	0.004	55%	46%	ns	49%	184/375

40% reported to have received (very) much information about Q fever vaccination. Most respondents perceived the received information to be comprehensive (87%) and reliable (90%; no differences were observed with regard to socio-demographic groups). Participants were also asked what their dominant feelings were regarding the action taken by the Dutch government to control Q fever; 49% reported negative feelings. Higher educated respondents reported negative feelings regarding governmental action more often than respondents in other educational brackets (p = 0.004). The most common negative feelings regarding governmental action that were reported by these respondents were negligence (55%; 101/184), disappointment (18%; 33/184) and irritation (16%; 30/184) (data not shown). However, 44% (166/375) reported positive feelings regarding governmental action taken to control Q fever; the most commonly reported positive feelings were confidence (47%; 78/166) and satisfaction (38%; 63/166) (data not shown).

Multivariate regression analyses for those outcome measures for which more than one demographic variable was significant in the univariate analyses, showed the following. Gender (p ‹ 0.001) and employment status (p = 0.01) remained significant regarding feelings of doubt. Information-seeking behavior correlated significantly with educational level (p = 0.02) and employment status (p = 0.03). Educational level (p = 0.002) and employment status (p = 0.03) remained significant regarding being informed via general practitioner. "Age" was no longer significant for these three dependent variables (resp. p = 0.7; p = 0.4; p = 0.4). Educational level remained significant regarding being informed via local/regional newspaper (p = 0.003) and being satisfied with the informing

Figure 1. Reasons for accepting Q fever vaccination among patients with specific cardiovascular conditions (n = 413)



Note that 183 respondents reported more than one reason; therefore the total sum is >100%.

method (p = 0.002); however, "employment status" was no longer significant regarding these two dependent variables (resp. p = 0.3; p = 0.2).

Discussion

With the aim of optimizing response rates in future vaccination campaigns, we studied underlying reasons for vaccination acceptance, risk perceptions, feelings of doubt, social influence, information-seeking behavior, preventive measures taken, and perceptions regarding received information and governmental action, among patients with specific cardiovascular conditions who accepted Q fever vaccination.

Our study is unique in that not a single study has been published about risk perception and public responses in case of a Q fever outbreak, or about Q fever vaccination acceptance. This study provides interesting results, especially in light of some unique aspects of Q fever vaccination in the Netherlands: 1) the Netherlands is the first country to offer Q fever vaccination to patients with specific cardiovascular conditions living in high-risk areas; 2) the Q fever vaccine (Q-VAX®) was not licensed for use in the

Netherlands, and therefore could only be administered after elaborate awareness and informed consent procedures had been completed; 3) vaccine efficacy and safety were previously tested on a selected group (mainly abattoir workers) [14-18]; 4) contrary to other vaccination programs (e.g. the routine National Immunization Program), pre-vaccination screening was required, including serum antibody and skin testing. An important strength of this study is that data collection took place immediately after vaccination, reducing the risk of recall bias and providing more reliable data compared with studies using hypothetical situations performed before the implementation of Q fever preventive measures. We used exit interviews, which are easier to complete for elderly patients (compared with, for example, self-administrated written questionnaires). Nearly one-third of all people in the Netherlands who were vaccinated against Q fever were interviewed, and high response rates (approximately 80%) were obtained. Therefore, we may conclude that our study can be considered representative for the entire group of patient with specific cardiovascular conditions who accepted vaccination in the Netherlands. The sample size was large enough to detect significant differences among demographic subgroups.

This study also has some limitations. First, the study population consisted of patients with specific cardiovascular conditions living in high risk areas in the Netherlands. This is a select group and generalization to the entire Dutch population or to other high-risk subgroups (such as pregnant women or immune suppressed persons) is therefore limited. Second, the validity of our questionnaires could not be tested using a test-retest design, because the Q fever outbreak was ongoing and perceptions were not stable over time. Third, this study has a cross-sectional design, and is therefore unable to describe changes in the decision-making process over time, or changes in causal pathways (e.g. does high perceived severity of Q fever result in fewer feelings of doubt towards vaccination). Fourth, no data could be collected regarding the decision-making process of patients who did not attend or declined Q fever vaccination. The group of eligible patients could not be targeted as a cohort, because no centralized database exists of patients with specific cardiovascular conditions living in high-risk areas in the south of the Netherlands. Therefore, the decision-making processes of Q fever vaccination among accepters and decliners could not be compared. Finally, the use of exit interviews may have created more social desirability bias than other data collection methods, such as sending questionnaires by mail.

Most respondents reported that being at risk for developing (chronic) Q fever was a reason for vaccination acceptance. Furthermore, the vast majority of the respondents agreed with statements regarding perceived severity (i.e. “Q fever is a severe disease”; “Q fever is very harmful for my health”). This finding is in agreement with a number of health-behavior-predicting theories and studies on vaccination behavior that describe a positive association of perceived vulnerability to and severity of the disease on preventive health behavior [27,28]. During future vaccination campaigns, it is important to provide information about the severity of the disease and individuals’ vulnerability to developing the disease, tailoring this information to specific risk groups.

“Recommendation of general practitioner” was frequently reported as a reason for Q fever vaccination acceptance among the study population, which is quite understandable

because people could be informed that they were member of a target group by their general practitioner. This fact may also explain why more than one-half of the respondents who solicited advice from their social networks regarding Q fever vaccination reported their general practitioner as a source of advice. For most respondents, the general practitioner played a key role in the decision-making process regarding Q fever vaccination. This finding is in agreement with other studies that conclude that physicians, especially general practitioners, are key social facilitators and an important source of information for the elderly in particular, regarding vaccination decisions [29-31]. To improve vaccine uptake among elderly patients during future outbreaks of infectious disease, general practitioners should be encouraged to motivate elderly patients to get vaccinated, and should provide knowledgeable and up-to-date information about the benefits and risks of vaccination.

One-third of all respondents reported feelings of doubt regarding their vaccination decision. This proportion was lower than expected, especially because the vaccine had not been licensed for use in the Netherlands and evidence on the Q fever vaccine's efficacy and safety was limited. Most respondents reported doubts related to fear of side effects, practical barriers, and the belief that the vaccine had not been thoroughly tested. Other studies have also concluded that concerns about vaccine safety and effectiveness negatively influence vaccine uptake [32-34]. Practical barriers were likely related to the fact that vaccination required two medical consultations seven days apart. Furthermore, vaccination was offered at one central Municipal Health Service, which made it more difficult for the target population, which mainly including elderly patients, to attend a pre-vaccination screening and vaccination session.

Approximately two-thirds of the respondents who asked for advice from their social networks reported that this advice influenced their vaccination decision. Social influence is an important construct and can be seen as a 'cue to action' described in a number of health-behavior predicting theories [27,28]. In addition to the general practitioner, family was an important source of advice among the study population. Zimmerman and Santibanez concluded that patients who were vaccinated were more likely than those who were unvaccinated to consider advice from friends and family members as important in affecting their health-related decisions [34].

Participants were asked about their dominant feelings regarding action taken by the Dutch government to control Q fever. This item was included because there has been an ongoing public debate in the media that has frequently resulted in negative attention towards governmental actions taken to control Q fever. For example, it was stated that governmental action was inadequate and the government perceived veterinarian interests as more important than public health. Despite the condemnation of the government in the media, patients who accepted Q fever vaccination were not overly negative and appeared to moderate the critical statements of the media; less than one-half of all respondents reported negative feelings regarding governmental actions taken to control Q fever.

As described in the results, for some outcome measures there was an interplay between demographic variables. Age highly correlated with employment status (older/retired), and employment status highly correlated with educational level (lower educated/unemployed).

Multivariate regression analyses showed that 1) employment status was a stronger determinant than age and 2) educational level was a stronger determinant than employment status. Nevertheless, vaccination decision-making may differ among socio-demographic subgroups. In our study, a number of significant differences in outcome measures were observed, regarding gender, age, educational level, and employment status. For example, compared with men, women more often reported feelings of doubt about the vaccination decision and feelings of worry that they might become infected with Q fever within the next 12 months. Similarly, compared with lower educated respondents, higher educated respondents more often reported information-seeking behavior. Differences among socio-demographic subgroups were also observed in other studies on vaccination decision-making regarding seasonal influenza and A(H1N1) [24,32,35-37].

Conclusion

This study identified the main reasons for vaccination acceptance and perceptions regarding Q fever among patients with specific cardiovascular conditions in the Netherlands. These results are useful for the development of effective risk communication. Vaccination decision-making may differ among socio-demographic subgroups. During the preparation of future vaccination campaigns, it is important to obtain greater insight into these differences and take these aspects into account in risk communication strategies by tailoring the information to specific target groups.

Authors' contributions
All authors contributed to the study design. MB and DB were centrally involved in the data collection process. Data analysis was performed by MB and HV. MB, DB, and HV wrote the first draft of the manuscript; DB, CW, AT, and JHR critiqued the manuscript and contributed to additional drafts. HV is the guarantor. All authors have read and approved the final manuscript.

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CHAPTER 8

Study on public perceptions and protective behaviors regarding Lyme disease among the general public in the Netherlands:

implications for preventions programs

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Abstract

Background
Lyme disease (LD) is the most common tick-borne disease in the United States and in Europe. The aim of this study was to examine knowledge, perceived risk, feelings of anxiety, and behavioral responses of the general public in relation to tick bites and LD in the Netherlands.

Methods
From a representative Internet panel a random sample was drawn of 550 panel members aged 18 years and older (8-15 November 2010) who were invited to complete an online questionnaire.

Results
Response rate (362/550, 66%). This study demonstrates that knowledge, level of concern, and perceived efficacy are the main determinants of preventive behavior. 35% (n = 125/362) of the respondents reported a good general knowledge of LD. While 95% (n = 344/362) perceived Lyme disease as severe or very severe, the minority (n = 130/362, 36%) perceived their risk of LD to be low. Respondents were more likely to check their skin after being outdoors and remove ticks if necessary, than to wear protective clothing and/or use insect repellent skin products. The percentage of respondents taking preventive measures ranged from 6% for using insect repellent skin products, to 37% for wearing protective clothing. History of tick bites, higher levels of knowledge and moderate/high levels of worry were significant predictors of checking the skin. Significant predictors of wearing protective clothing were being unemployed/retired, higher knowledge levels, higher levels of worry about LD and higher levels of perceived efficacy of wearing protective clothing.

Conclusion
Prevention programs targeting tick bites and LD should aim at influencing people's perceptions and increasing their knowledge and perceived efficacy of protective behavior. This can be done by strengthening motivators (e.g. knowledge, concern about LD, perceived efficacy of wearing protective clothing) and removing barriers (e.g. low perceived personal risk, not knowing how to recognize a tick). The challenge is to take our study findings and translate them into appropriate prevention strategies.

Keywords
Perceptions, Lyme disease, Ticks, Tick bites, General public, Prevention, Protective behavior, Knowledge, Concern

Background

Lyme disease (LD) is the most common tick-borne disease in the United States and in Europe. In the Netherlands, the number of General Practitioner (GP) consultations for tick bites has increased from 191 per 100,000 in 1994 to 564 per 100,000 in 2009 [1]. In 1994, the incidence of patients visiting the GP for Erythema migrans (EM, an asociated symptom) was estimated at 39 per 100,000 inhabitants. This number increased to 134 per 100,000 in 2009 [1]. Similar trends have been observed in other European countries [2]. The emergence of Lyme borreliosis may have been partly caused by an increased awareness among citizens and medical personnel, and changes in pathogen and vector populations [3].

Transmission of LD requires the presence in the area of: (1) the spirochete *Borrelia burgdorferii* sensu lato (in Europe) in an animal reservoir that is capable of transmitting the spirochetes to feeding ticks; (2) the vector, in European ticks belonging to the *Ixodes ricinus* group; and (3) susceptible hosts, including humans. Forested areas and recreational sites such as parks and gardens are associated with a higher risk of tick bites [4].

In humans LD develops in three stages. In the first stage (the early localized infection), people may experience fever, headache, fatigue and depression. The most commonly recognized symptom at this stage (occurring in about 90% of patients) is a circular red skin rash around the place of the tick bite: erythema migrans. Antibiotics administered at this stage will prevent further stages developing. Untreated, the infection may spread from the site of the bite to other parts of the body, producing an array of distinct symptoms that may come and go, including: additional EM lesions in other areas of the body, facial or Bell's palsy (loss of muscle tone on one or both sides of the face), severe headaches and neck stiffness due to meningitis (inflammation of the spinal cord), pain and swelling in the large joints (such as knees), shooting pains that may interfere with sleep, heart palpitations and dizziness due to changes in the heartbeat. This is called the second stage (early disseminated stage). Many of these symptoms will resolve over a period of weeks to months, even without treatment. However, a lack of treatment can result in additional complications. Approximately 60% of patients with an untreated infection may begin to have intermittent bouts of arthritis, with severe joint pain and swelling. Without treatment, LD enters the third stage after several months. During this stage, the patients develop chronic symptoms that can affect a wide range of body parts, including the brain, nerves, joints and the heart [5].

Recommendations for first line treatment from most European countries and the USA specify doxycycline or amoxicillin, with minor differences in doses and treatment duration. Both agents have proven efficacy, but a small proportion of patients have persistent symptoms following appropriate treatment for LD [6]. Because no vaccine is available and effective measures for controlling tick populations are still in the experimental phase or insufficient, health education is considered the most important approach for preventing LD. The National Institute of Public Health and The Environment (RIVM) provides information on public health topics to professionals and to the general public. This includes a national guideline on the prevention and control of LD for professionals [7] and several brochures for the general public. In the Netherlands, the local public health

services are responsible for sending out the guideline and brochures to professionals (e.g. GP's, camping holders) and to the public.
Preventive strategies include the avoidance of tick-infested areas, the use of protective clothing (e.g. wearing long-sleeved shirts and long trouserpants, which reduce the area of exposed skin), routine body checks for ticks after being outdoors, and the use of tick repellents on either the skin or clothing.

Despite the availability of Lyme prevention advice, public compliance with the LD-guidelines could be improved [8]. Surveillance of perceptions and behavioral responses of the general public to ticks and LD is required for improving health risk communication and achieving successful changes in public behavior [9-13].

However, in the Netherlands very little is known about the perception and protective behavior of people in relation to the prevention of tick bites and LD [14]. In 2010 Maat and Konings found in their study among 600 residents in the Southwest of the Netherlands that many respondents lacked skills for recognizing and removing ticks, underestimated their personal risk for tick bites and found protective measures exaggerated [15]. They concluded that new prevention strategies should focus on self-efficacy, risk perception, and the presentation of alternative measures, e.g. skin check instead of wearing protective clothing.

In the present study our aim was to examine the knowledge, perceived risk, feelings of anxiety, and behavioral responses of the Dutch general public related to ticks and LD. The questionnaire was based on an integrated model to explain health behavior, including constructs from the Protection Motivation Theory and the Health Belief Model [16,17]. Protection Motivation theory has been used as a model for predicting health behavior. A threat appraisal is formed by an individual based on their perceived likelihood of a particular event occurring and their perceived severity of the event. The way in which an individual chooses to respond to a threatening situation is termed their coping appraisal, and is based on both the belief that uptake of a recommended behavior will resolve the threat (response efficacy), and an individual's belief in his/her own ability to effectively perform the behavior (self-efficacy). In the Health Belief Model, perceptions of the individual are at the core of the model, which posits that the beliefs of individuals about their own susceptibility to a health threat, their perceptions about the severity of that threat, and their perceptions about the benefits and barriers associated with a particular protective action, will determine whether or not they adopt that action. Extensions to the model suggest that the 'self-efficacy' (their belief in their own ability to perform a given behavior) of an individual also plays a strong role in determining whether a behavior is adopted, as does the existence of cues to action that prompt or remind someone to engage in a particular behavior.

The results will act as a guide for further development of effective LD prevention programs by identifying those measures most likely to be adopted by the general public in the Netherlands.

Methods

Participants

For this study a representative Internet panel was used, named the Flycatcher panel (http://www.flycatcher.eu). This panel consists of members from the Dutch general public who volunteer to participate in online questionnaire surveys. The panel consists of 20.000 members with a representative distribution of demographic variables (gender, age, region, and level of education) for the general Dutch population. The panel meets high quality requirements and is ISO-certified. A random sample of 550 panel members aged 18 years and older was drawn. Panel members in this selection were invited to participate in this study by sending an email with a linking to an online questionnaire. The survey remained online from 8 to 15 November 2010. No reminders were sent out. To motivate enrollment, participants received 1.50 Euro in credits for completion of the survey, which could be exchanged for gift vouchers.

The nature of this general Internet-based survey among healthy volunteers from the general population does not require formal medical ethical approval according to Dutch law [18].

Questionnaire

The online questionnaire (45 questions) was developed based on an existing questionnaire used in studies on risk perception and precautionary behaviors of the general public during the 2009-H1N1 flu pandemic and during outbreaks of SARS and avian Influenza [19-21].

To examine people's perceptions of LD and the preventive measures and the predictors of protective behavior we included the following constructs: knowledge, perceived severity of and vulnerability to LD, feelings of concern, perceived efficacy of preventive measures, a person's ability (self-efficacy) and intention to take measures, actual behaviors, and main motivators and barriers taking measures. Knowledge was examined according to five statements concerning modes of transmission, incidence of tick bites and preventive measures. For knowledge, a summary score was created based on the number of correct answers and dichotomized as 0 (≤3 items correct) or 1 (4-5 items correct). Perceived severity was measured by two items, namely "How serious do you think Lyme disease is?" and "How awful would it be if you were diagnosed with Lyme disease in the next 12 months?". Perceived vulnerability was also measured by two items, namely "Do you think that you are susceptible getting LD, if you don't take preventive measures?" and "How likely is it that you will be diagnosed with LD in the next 12 months?". Feelings of concern were measured by asking respondents "How worried are you about getting LD?".

Participants were asked about four preventive measures for LD, namely: 'wearing protective clothing that cover the body (i.e. long trousers/sleeves)'; 'using insect repellent skin products'; 'checking the skin after being outdoors' and 'removing ticks from the skin'. Perceived efficacy of these preventive measures was formulated as "Do you think [*measure X*] helps to prevent Lyme disease?"; self-efficacy as "Do you think you are able to perform [*measure X*]?"; intention as "Do you intend to perform [*measure X*]?'; and behavior as "How often do you perform [*measure X*]?". People who indicated that they

had never performed a certain preventive behavior were asked to tick a maximum of three barriers from a list of possible barriers (to which they could add their own barrier); people who indicated that they had sometimes/often/always performed a certain behavior were asked to tick a maximum of three motivators from a list of possible motivators (to which they could and their own motivator). Barriers and motivators were generated from the literature (including unpublished/grey literature) [15,22-24].

Analysis

Descriptive statistics were performed. Due to skewed distributions, and to aid interpretation of the results, constructs were dichotomized into low and high scores *(see Table 1)*, and the Chi-squared test was used to test the statistical significance of group differences (gender, age, educational level, and employment status) regarding knowledge, perceived severity, perceived vulnerability, feelings of concern, perceived efficacy of preventive measures, perceived self-efficacy, intention and preventive measures taken.

Univariate and multivariate logistic regression analyses were performed to identify factors significantly associated with 1) wearing protective clothing and 2) checking skin after being outdoors. For the multivariate regression analyses, a backward 'elimination' procedure was employed, starting with all potential independent variables (all variables with a p-value ‹0.1 in the univariate analysis), and then with the least significant variable removed at each step (the one with the highest p-value), until only statistically significant predictors ($p < 0.05$) remained.

Results

A total of 550 panel members were invited to participate in this study, of whom 362 completed the questionnaire (response rate 66%). Of the 362 respondents, 51% was female (data not shown). The age varied from 18-29 years (14%), 30-49 years (35%) and ≥50 years (51%). Thirty-seven percent had a low educational level (i.e. primary education, lower general or lower vocational education or less), 38% an intermediate (i.e. secondary general or vocational education), and 25% a higher education (i.e. higher professionals education or university). More than half of the respondents were employed, and in 36% of the households there were one or more children. The overall majority were of Dutch origin. Most respondents lived in the middle (45%) and the south (46%) of the Netherlands. Twelve percent of the respondents had had a tick bite once and 9% had repeatedly had tick bites in the Netherlands. Around half of the respondents were regularly (every week/once a month) physically active in a garden, 37% visited the woods regularly and 21% visited open areas regularly.

Knowledge

Of the respondents, 125 (35%) answered at least 4 out of 5 knowledge statements correctly *(Table 1)* and were categorized as having "good general knowledge". The statements "people can get LD after a tick bite" and "during the summer, the chance of tick bites is higher compared to the winter" were correctly answered by the majority of the respondents (98% and 90% respectively; data not shown). Remarkably, only 22% were aware that "using repellent skin products can protect against tick bites".

Perceived severity and vulnerability
Of the respondents, 95% perceived LD to be severe or very severe, significantly more often by female (n = 179, 97%) than by male respondents (n = 165, 93%), (p = 0.047). Equally, (n = 345), 95% reported that it would be awful or very awful if they were diagnosed with Lyme disease in the next 12 months, while 36% (n = 130) perceived themselves as quite/very susceptible, and only 4% believed it was likely or very likely that they would be diagnosed with Lyme disease in the next 12 months. Around half of the respondents reported feelings of concern about getting LD, significantly less frequently in respondents aged 18-29 years (n = 19, 37%) compared to the other age groups (n = 176, 57%) (p = 0.03).

Self-efficacy, response efficacy and intention
Wearing protective clothing and checking the skin after being outdoors were perceived as the most effective measures for preventing tick bites. Respondents aged 18-29 and those employed reported high perceived efficacy of wearing protective clothing less often (p = 0.005 and p = 0.01 respectively), whereas male respondents reported high perceived efficacy of checking the skin (p = 0.04) less often. Almost three quarters reported high perceived efficacy of removing a tick from their skin, and only a minority of the respondents (34%) reported high perceived efficacy of using repellent skin products. The majority of respondents reported high perceived self-efficacy for removing ticks from their skin (74%) and checking their skin after being outdoors (64%). Female respondents (p = 0.03) reported high perceived self-efficacy of checking their skin after being outdoors more often. Only 39% reported high perceived self-efficacy of wearing protective clothing, which was more often reported by respondents aged 50 years and older and those unemployed/retired (resp. p = 0.04 and p = 0.005 respectively). High perceived self-efficacy of using repellent skin products was reported by 30% of the respondents. Female respondents (p < 0.001) and lower educated (p = 0.045) reported high perceived self-efficacy for using repellent skin products more often.

The overall majority (93%) reported a high intention to remove a tick from their skin, if necessary, and 53% reported high intention for checking their skin. High intention to wear protective clothing was observed in 38% of the respondents. Respondents aged 50 years and older (p < 0.001), those with a lower education (p = 0.04) and unemployed/retired (p < 0.001) reported high intention to wear protective clothing more often. Twenty-two percent of the respondents reported high intention for using insect repellent skin products. Female respondents reported high intention to use repellent skin products more often (p = 0.03).

Preventive measures taken
Thirty-seven percent of the respondents reported wearing protective clothing when going into nature areas (30% who reported this behavior often and 8% always; data not shown). Unemployed/retired respondents reported to wear protective clothing more often compared to those employed (p = 0.002). Thirty-two percent of the respondents reported checking their skin after they had been outdoors (21% often and 11% always). A minority (6%) reported to use insect repellent skin products (5% often and 1% always).

Table 1 Perceptions regarding Lyme disease and preventive measures (n=362)

	Gender			Age		
	Male (%)	Female (%)	p-Value	18-29 (%)	30-49 (%)	≥50 (%)
Knowledge (5 statements)[1]						
4 or 5 correct	31	38	ns	31	35	35
Perceived severity (scale 1-5; not at all – very severe/awful)						
Seriousness of LD						
score 4-5 (severe/very severe)	93	97	0.047	96	97	94
Severity being diagnosed with LD in the next 12 months						
score 4-5 (awful/very awful)	94	97	ns	100	96	94
Perceived vulnerability (scale 1-5; not at all – very susceptible/likely)						
Susceptibility to LD						
score 4-5 (quite susceptible/very susceptible)	38	34	ns	43	33	36
Likelihood being diagnosed with LD in the next 12 months						
score 4-5 (likely/very likely)	4	4	ns	2	4	5
Feelings of concern (scale 1-5; not at all – very worried)						
score 3-5 (a bit worried/worried/very worried)	51	55	ns	37	60	54
Perceived efficacy (scale 1-5; certainly not – certainly)						
Wear protective clothing (score 4-5)	92	89	ns	78	91	94
Check your skin after being outdoors (score 4-5)	79	87	0.04	88	81	84
Remove tick from your skin (score 4-5)	73	71	ns	73	69	74
Use insect repellent skin products (score 4-5)	31	37	ns	31	39	31
Perceived self-efficacy (scale 1-5; certainly not – certainly)						
Wear protective clothing (score 4-5)	40	37	ns	35	31	45
Check your skin after being outdoors (score 4-5)	59	69	0.03	69	62	64
Remove tick from your skin (score 4-5)	77	72	ns	78	71	75
Use insect repellent skin products (score 4-5)	21	38	<0.001	26	33	29
Intention (scale 1-5; certainly not – certainly)						
Wear protective clothing (score 4-5)	39	38	ns	24	29	49
Check your skin after being outdoors (score 4-5)	48	58	ns	53	54	52
Remove tick from your skin (score 4-5)	92	93	ns	88	91	96
Use insect repellent skin products (score 4-5)	17	27	0.03	20	25	21
Behavior (scale 1-4; never - always)						
Wear protective clothing (score 3-4)	39	36	ns	28	33	43
Check your skin after being outdoors (score 3-4)	30	34	ns	39	31	30
Use insect repellent skin products (score 3-4)	7	6	ns	6	8	5

LD = Lyme Disease;

[1] *The five statements were: people can get Lyme disease after a tick bite; during the summer, the chance on tick bites is higher compared to the winter; ticks mostly fall out of trees; about 1 in 15 people in the Netherlands are yearly bitten by ticks; using repellent skin products can protect against tick bites*

	Education				Employment status			Overall	
p-Value	Low (%)	Middle (%)	High (%)	p-Value	Employed (%)	Unemployed/ retired (%)	p-Value	%	n/ntot
ns	33	35	36	ns	32	38	ns	35	(125/362)
ns	94	97	93	ns	95	95	ns	95	(344/362)
ns	96	96	95	ns	95	95	ns	95	(345/362)
ns	31	35	44	ns	38	33	ns	36	(130/362)
ns	3	7	2	ns	5	3	ns	4	(15/362)
0.03	53	55	52	ns	56	50	ns	53	(193/362)
0.005	90	91	90	ns	87	95	0.01	90	(327/362)
ns	82	85	84	ns	82	85	ns	83	(302/362)
ns	68	79	67	ns	72	72	ns	72	(260/362)
ns	31	39	31	ns	36	31	ns	34	(123/362)
0.04	44	33	39	ns	33	47	0.005	39	(140/362)
ns	67	68	54	ns	63	65	ns	64	(232/362)
ns	69	77	79	ns	74	75	ns	74	(269/362)
ns	36	29	21	0.045	28	32	ns	30	(108/362)
‹0.001	46	37	30	0.04	28	52	‹0.001	38	(139/362)
ns	53	57	47	ns	53	54	ns	53	(192/362)
ns	93	92	93	ns	91	95	ns	93	(336/362)
ns	26	23	15	ns	22	23	ns	22	(80/362)
ns	37	38	36	ns	31	46	0.002	37	(135/362)
ns	27	38	29	ns	32	31	ns	32	(115/362)
ns	7	4	8	ns	7	5	ns	6	(22/362)

Table 2. Predictors of wearing protective clothing to prevent tick bites

	Wearing protective clothing (often/always)						
		Univariate			Multivariate		
Characteristics	Row %	OR	95% CI	p-Value	OR	95%CI	p-Value
Employment status							
employed	31	1.00			1.00		
unemployed/retired	46	1.96	1.27-3.03	0.002	1.96	1.24-3.08	0.004
Knowledge							
1-3 statements correct	33	1.00			1.00		
4-5 statements correct	46	1.80	1.15-2.81	0.01	1.69	1.07-2.68	0.03
Feelings of concern							
not (at all) worried (1-2)	28	1.00			1.00		
a bit/(very) worried (3-5)	45	2.07	1.34-3.21	0.001	2.22	1.41-3.51	0.001
Perceived efficacy							
certainly not, probably not, even (1-3)	17	1.00			1.00		
certainly/probably (4-5)	39	3.15	1.27-7.80	0.01	2.97	1.17-7.54	0.02

Gender, age, education, children in household, ethnicity, region of residence in the Netherlands, experienced tick bites in past, frequency of visiting nature, perceived severity (2 items) and perceived vulnerability (2 items) were not univariately associated with wearing protective clothing.

Determinants of preventive behavior

Univariate and multivariate logistic regression analyses were performed to identify factors significantly associated with 1) wearing protective clothing and 2) checking the skin after being outdoors. *Table 2* shows significant predictors of wearing protective clothing that were selected using the univariate logistic regression. From the multivariate logistic regression analysis, predictors of wearing protective clothing were: being unemployed/retired (OR 1.96; 95% CI 1.24-3.08), higher knowledge levels (OR 1.69; 95% CI 1.07-2.68), higher levels of concern about LD (OR 2.22; 95% CI 1.41-3.51) and higher levels of perceived efficacy of wearing protective clothing (OR 2.97; 95% CI 1.17-7.54). *Table 3* shows significant predictors of checking the skin for the presence of ticks. From the multivariate logistic regression analysis, predictors of checking the skin were: experienced tick bites in the past (OR 2.19; 95% CI 1.27-3.78), higher knowledge levels (OR 2.83; 95% CI 1.74-4.58) and higher levels of concern about LD (OR 2.81; 95% CI 1.71-4.60).

Main motivators and barriers

Respondents were asked to identify the main motivators and barriers for wearing protective clothing, using insect repellent skin products and checking skin/removing ticks from their skin *(Table 4)*. Overall, the main motivators that were mentioned were: the perceptions that LD can be severe, the perception that the preventive measure is effective in preventing tick bite/LD, a person's feeling of responsibility regarding his/her health and the perception that there is a high chance of tick bites. Among the 78 respondents who did not wear protective clothing, 81% reported that as a barrier, wearing protective clothing in summer is too warm; 30% reported a low risk of tick bites and 23% perceived that wearing protective clothing in nature areas is overdone. Of the 276 respondents who did not use insect repellent skin

Table 3 Predictors of checking skin for the presence of ticks to prevent Lyme disease

	Checking skin (often/always)						
		Univariate			Multivariate		
Characteristics	Row %	OR	95% CI	p-Value	OR	95%CI	p-Value
Experienced tick bites in the past							
no, never	27	1.00			1.00		
yes, once/repeatedly/outside NL	48	2.48	1.48-4.14	0.001	2.19	1.27-3.78	0.005
Knowledge							
1-3 statements correct	24	1.00			1.00		
4-5 statements correct	47	2.89	1.82-4.59	‹0.001	2.83	1.74-4.58	‹0.001
Perceived susceptibility							
not (at all) susceptible (1-3)	25	1.00					
(very) susceptible (4-5)	44	2.34	1.48-3.70	‹0.001	-	-	-
Likelihood being diagnosed with Lyme disease in next 12 month							
not (at all) likely (1-2)	25	1.00					
a bit/(very) likely (3-5)	39	1.92	1.23-3.01	0.004	-	-	-
Feelings of concern							
not (at all) worried (1-2)	20	1.00			1.00		
a bit/(very) worried (3-5)	43	3.04	1.89-4.90	‹0.001	2.81	1.71-4.60	‹0.001

Gender, age, education, employment status, children in household, ethnicity, region of residence, frequency of visiting nature, perceived severity of Lyme disease (2 items) and perceived efficacy were not univariately associated with checking skin.

products, 34% did not believe these products to be effective, 32% did not like to use insect repellent products on their skin and 27% reported that too little information is provided about preventing tick bites through insect repellent skin products. Of the 108 respondents who did not check their skin/remove tick, 35% perceived low risk of tick bites, 19% did not know how to recognize a tick, 19% thought checking the skin after being outdoors is overdone, and 16% did not know how to remove a tick or reported that too little information is provided.

Discussion

In this study we identified the main predictors and motivators that influence protective behavior for preventing tick bites and LD. We did this by investigating the knowledge, perceptions and efficacy beliefs of healthy people in the general population in the Netherlands, a country in which the incidence of LD has increased sharply throughout the past two decades.

Insight into public perceptions and protective behavior regarding LD is crucial in order to develop a successful prevention program [9]. We conclude that good general knowledge about preventing tick bites and LD is scarce, while the perception of risks and self-efficacy of the measures varies greatly among the respondents.

Table 4 Main motivators and barriers for measures to prevent tick bites

Wearing protective clothing	%
Motivators (n=284)	
"wearing protective clothing is effective"	53
"high perceived chance of tick bites"	47
"Lyme disease can be severe"	37
"feel responsible for my health"	33
"I follow the advice"	19
Barriers (n=78)	
"wearing protective clothing during summer is too warm"	81
"low perceived chance of tick bites"	30
"wearing protective clothing in nature is overdone"	23
"low perceived chance of Lyme disease"	19
Using insect repellent skin products	
Motivators (n=86)	
"Lyme disease can be severe"	45
"feel responsible for my health"	40
"high perceived chance of tick bites"	38
"using repellent skin products is effective"	34
"I follow the advice"	29
Barriers (n=276)	
"do not belief it is effective"	34
"do not like to use insect repellent products for my skin"	32
"too little information is provided"	27
"low perceived chance of tick bites"	23
"using insect repellent skin products is overdone"	22
"I am not familiar with insect repellent skin products"	19
Checking skin after being outdoors/remove tick	
Motivators (n=353)	
"Lyme disease can be severe"	64
"checking skin/remove tick is effective"	48
"feel responsible for my health"	44
"I follow the advice"	25
"high perceived chance of tick bites"	18
"high perceived chance of Lyme disease"	16
Barriers (n=108)	
"low perceived chance of tick bites"	35
"do not know how to recognize a tick"	19
"check my skin after being outdoors is overdone"	19
"do not know how to remove a tick"	16
"too little information is provided"	16

**Reasons reported by <15% of the respondents are not included in this table.*

Only 35% of the respondents reported a good general knowledge of LD, and only a quarter were aware that using repellent skin products can protect against tick bites. Suboptimal public knowledge regarding LD was also found in other studies in endemic areas. For example, Heller et al conducted a questionnaire study among 103 Brazilian residents -living in a Lyme disease endemic area in the United States-, and reported that 36% of the respondents had never heard of the disease and 62% were not certain they could recognize the symptoms [9]. Higher levels of knowledge seem to be positively associated with protective behavior as demonstrated by Gould et al. [10]. However, research in areas where LD is endemic has demonstrated that despite adequate knowledge about its symptoms and transmission, many people do not perform behaviors to reduce their risk of infection [25]. These findings suggest that a lack of knowledge is not the only reason for poor uptake of protective behavior.

Nearly all respondents perceived high severity of LD, but perceived vulnerability and feelings of anxiety were lower. The fact that the majority of the respondents perceived low personal risk of LD, implicates some public underestimation, especially, given the fact that people in the Netherlands, in particular those who often visit woodland areas, have a real risk of getting tick bites and developing LD [26]. The underestimation of risk is found to have been caused by factors such as lack of knowledge. Furthermore, if people underestimate their personal risk they will be less willing to engage in preventive behavior [13,27].

Higher levels of self-efficacy, respons efficacy and intention were observed for checking the skin after being outdoors and removing ticks if necessary. However, lower levels of (self-)efficacy and intention were observed for wearing protective clothing and using insect repellent skin products. The fact that most respondents in our study were unaware that using repellent skin products can protect against tick bites, might also be related to the lower levels of intention to use these products.

The percentage of respondents taking preventive measures ranged from 6% for using insect repellent skin products, to 40% for wearing protective clothing. These percentages are rather low, compared to other studies. Studies in the US reported that 66%-99% of the respondents took measures to prevent LD [10,22,23]. Furthermore, Heller et al found that the majority (78%) of the Brazilian respondents wore long trousers when outdoors and Herrington reported that one-half of the US respondents also did this [9,24]. The lower levels of wearing protective clothing in the Netherlands, especially in the summer, could be caused by the climate. The Netherlands has a maritime climate, with cool summers and an average temperature of 19 ºC in July. People in the Netherlands like wearing (light) clothing, such as shorts and short sleeved shirts, if the temperature increases. Also the fact that people believe that wearing protective clothing in nature areas is overdone, as reported in this study, might be a reason for the low levels of wearing protective clothing as reported by Cartter et al. [13].

One-third of the respondents in our study reported checking their skin after being outdoors. This is comparable with other studies; i.e. Heller et al who described that only 28% of the Brazilian population check their skins for ticks [9]. The main barriers for checking skin for ticks reported in our study were low perceived personal risk and not knowing how to recognize a tick.

Only 6% of our respondents reported using repellent skin products. The low use of insect repellent skin products was also been found in other studies. For example, in Brazil and the US 66% and 69% of the respondents respectively never used insect repellent skin products for protection against LD [9]. In our study a barrier for using repellent skin products is that people are not convinced about their efficacy or do not like to use these products. Herrington investigated barriers for using insect repellent skin products, and found that a substantial proportion of US respondents believed that using insect repellent could make them ill [24]. This underlines the need for people to "believe" in the effectiveness of a recommended behavior as well as they should have appropriate knowledge on the subject.

There were some differences in public perceptions regarding LD among socio-demographic subgroups. For example, females reported higher levels of perceived efficacy and self-efficacy to check their skin after being outdoors, whereas older respondents (≥ 50 yrs) reported higher levels of perceived efficacy, self-efficacy and an intention to wear protective clothing. However, in multivariate analysis, of all socio-demographic variables only employment status remained a significant predictor for wearing protective clothing for preventing tick bites.

As reported in our study, having had tick bites in the past, higher levels of knowledge and moderate/high levels of concern were significant predictors for checking the skin. Significant predictors of wearing protective clothing were being unemployed/retired, higher knowledge levels, higher levels of concern about LD and higher levels of perceived efficacy of wearing protective clothing. These findings are in accordance with Herrington [24], reporting that having seen ticks, being concerned about being bitten, having heard about LD and knowing someone who had LD are the factors most predictive of specific tick-bite protective behavior. Mowbray et al. showed in his review that both knowledge and attitudes towards tick-borne disease are amenable to change via an education campaign [28]. Unfortunately, in his systematic review of all previous studies that assessed the impact of education or behavioral interventions on the uptake of behaviors intended to protect against tick-borne diseases he could find only nine studies, of which only three took the form of a randomized controlled trial (RCT) [28]. One RCT studied the willingness to the uptake of a vaccine for LD and two focussed on other protective measures. Lawless et all used an instructional video with a mock horror movie theme to improve knowledge, attitudes, and behaviors towards LD prevention in 13- to 16-year-olds from four Connecticut towns [29]. One month and six months after seeing the video, knowledge, attitudes and behavior had increased significantly in the intervention group. Another study investigating the effectiveness of an educational intervention was performed by Daltroy et al. In over 30000 passengers on ferry boats to a Lyme-endemic area of Nantucket Island. In this study controls received education about bike safety, while intervention participants received information on preventing tick-borne disease,

particularly LD. Information was delivered on board by entertainers to make the messages more compelling. Two months after the intervention, experimental participants were more likely than controls to adopt precautionary behaviors, as well as to check themselves daily for ticks. In conclusion, future prevention programs for LD should focus on improving public knowledge, i.e. with regard to disease severity and vulnerability, efficacy of measures and on how to take preventive measures.

This is the first national study to evaluate the perceived LD-risk and protective behavior for LD in the general public in the Netherlands. Nevertheless, there are a number of limitations to our study. The majority of respondents (51%) was older than 50 years. This may have limited the generalizability of the results, although older age has not been found to be a distinct factor associated with compliance to preventive measures for LD found in previous studies. Furthermore, potential selection bias may have been introduced in that only respondents with a computer were interviewed by this online survey. Finally, cross sectional studies can prove a rich baseline of data points but should not be used to make causal statements, given the lack of a temporal sequence of events.

Conclusion

Our study has several implications for the development of LD prevention programs. It demonstrates that knowledge, level of concern and perceived efficacy of measures are the main determinants of preventive behavior. Therefore future prevention programs should focus on these determinants, for example, by providing facts and raising awareness about LD and protective measures that can be taken. Since protective measures like wearing protective clothing and using insect repellents are not 'popular', it is important that prevention programs focus on removing any barriers for complying with these protective measures, especially in people who have never had tick bites and those who are less concerned about the risks. Furthermore, it is important to tailor the information to specific socio-demographic subgroups and high risk groups.

Promoting preventive measures for LD is really important since reducing the tick population and developing a vaccine can only be seen as long-term solutions for the problems. The results of this study can be used as a base for developing effective prevention programs that connect with the needs of the target group, with the main goal to increase compliance with recommended measures.

The challenge is to take the principles demonstrated in this study and apply them to prevention programs. Some work in this area has already been done. Last year the Netherlands National Institute of Public Health and The Environment redesigned the national public information campaign on ticks and LD in the Netherlands. In this campaign the focus was shifted. First, not all possible evidence based preventive measures on LD were presented in the communication, instead the focus was placed on checking the skin and removing ticks. Also a educational game was developed, called in Dutch: "Teekcontrol.nl", to teach children playfully about ticks and LD. In this online game children can discover where ticks are most likely to be found and why it is important to check the skin after playing outdoors. Within 8 months of launching over 30.000

children had played this game. The learning effect of the game will be evaluated in 2012. Furthermore, a mobile phone app on ticks and LD is currently being developed. This will be based on a user- centered design. This means that the public will determine the features of this application.

Competing interests
The authors declare that they have no competing interests.

Authors' contributions
All authors contributed to the study design. DB, MB, and HV played major roles in the data collection process. Data analysis was performed by MB and HV with advice from DB and JvS. DB, MB and JvS wrote the first draft of the manuscript; HV critiqued the manuscript and contributed to further drafts. All authors read and approved the final manuscript.

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CHAPTER 8

General discussion

In this chapter, the three research questions as stated in the introduction are answered based on the studies described in this thesis. The findings will be discussed in relation to the international literature. This chapter ends with general conclusions and recommendations for optimising risk communication during future emerging infectious disease outbreaks and implication for further research.

9.1 Main findings

9.1.1 Research question 1

What are common patterns in trends over time in risk perception and preventive behaviour of the general public during outbreaks of emerging infectious diseases?

Trends over time in public risk perception and behavioural responses are generally in line with the course and severity of the outbreak, i.e. number of (new or fatal) cases. The amount of attention media choose to give to an outbreak as well as the way the media present messages also exerts a strong influence on public perception and behaviour.

We conducted a follow-up study during the 2009 Influenza A (H1N1) pandemic *(chapter 2 and 3)*. The first survey was carried out at the end of April 2009, when the first case was confirmed in the Netherlands [1]. The second survey started in June 2009, when there was sustained transmission of the virus in several countries and the WHO raised the pandemic alert status to phase 6, characterized by human-to-human spread and community level outbreaks in more than one WHO region [2]. The third survey was conducted in August 2009, when the Netherlands counted over 1000 confirmed cases, including the first fatal death [1]. In November 2009, around 900 hospitalizations and 22 fatal cases due to Influenza A (H1N1) were reported in the Netherlands [1]. In that month, a vaccination campaign for high-risk groups was implemented [3], and the fourth survey was conducted. We found that levels of knowledge, perceived vulnerability, and the proportion of respondents that took preventive measures increased during the pandemic. These trends are in accordance with the course of the pandemic. However, perceived severity, feelings of anxiety, perceived self-efficacy, and intention to comply with preventive measures decreased during the pandemic. This was probably caused by the fact that initially, representatives of (inter)national health institutes predicted a worse-case scenario with large numbers of fatal cases, based on influenza pandemics in the past and early reports concerning pandemic potential of the H1N1 virus [4]. In the following months, media attention decreased considerably, local virus transmission remained relatively limited in the Netherlands, and the Dutch government announced that the pandemic appeared to be mild [5,6].

We also conducted a follow-up study during the Q fever epidemic *(chapter 6)*. The first survey was carried out in August 2009 when the number of Q fever cases in the Netherlands reached a peak of 2,357 (including 7 fatal cases) [7,8]. The second survey took place in April 2010, when 208 human cases were identified in the period January to May 2010; this was lower than the number identified in the same period in 2009 [9]. In 2010, a total of 504 Q fever cases were reported in the Netherlands, including 11 fatal

cases [7,9]. The third survey took place in April 2012, when the incidence had largely dropped off (66 cases in 2012, including 1 fatal case) [7]. At the end of 2012, the National Institute of Public Health and the Environment declared the end of the Q fever epidemic [10]. Between 2009 and 2010, we found increases in public knowledge, perceived severity, anxiety, perceived efficacy of measures, and actual preventive behaviour. Furthermore, increasing trends were observed in amount of information respondents received and attention paid to this information. These increasing trends coincided with marked increases in media attention to the Q fever epidemic in the Netherlands in late 2009 and early 2010, and the implementation of drastic veterinary measures, such as a culling campaign for pregnant dairy goats and sheep on infected farms (a total of 50,000 goats were culled on 88 infected farms) [8,9]. Between 2010 and 2012, public knowledge, perceived anxiety, and preventive behaviour decreased. The amount of information respondents received and attention paid to the information on Q fever also decreased. These findings are in line with the decreasing number of new cases and media attention on the Q fever epidemic in the Netherlands.

Besides these follow-up studies, we performed a systematic literature review on trends over time in risk perception and behaviour of the general public during the 2009 Influenza A (H1N1) pandemic *(chapter 5)*. We extracted trends over time from longitudinal studies, follow-up studies or studies with multiple cross-sections, i.e. measuring real trends. Studies included in this review also described increasing trends in perceived vulnerability during the early and pandemic peak phases among the general public in the US [11], Hong Kong [12], and the Netherlands [13]. Furthermore, comparable with the findings of our studies, studies conducted in the US, Hong Kong, and Italy also found decreasing trends in perceived severity, perceived anxiety and/or intention to comply with preventive measures like vaccination [11-15]. Trends in preventive behaviour differed for specific measures and the pandemic phase in which data collection took place. In our study, practicing better hygiene increased over time during the pandemic peak and post pandemic phases, whereas studies conducted in Hong Kong reported that practicing better hygiene remained high and stable during the early, pandemic peak, and post pandemic phases [12,14]. Furthermore, a study in Malaysia reported increasing trends in staying at home, taking preventive medicine, and wearing masks between July and September 2009, whereas washing hands regularly declined from half August 2009 when the number of deaths decreased [16]. During the pandemic, decreasing trends were also observed in avoidance behaviour (i.e. avoiding public transport and crowded places), as reported in studies conducted in Hong Kong [12,14] and Italy [15].

Although trends over time in risk perception and behavioural responses of the public are generally in line with the course and severity of the outbreak, risk perception of the public is largely formed by the amount of media attention and the way messages in the media are presented or "framed", which in turn may have an influence on public response. Contrary, public perception and behaviour may also influence the amount of media attention and the way the media messages are presented. There are numerous frames used by the media to communicate and structure its message [17-20]. Examples of commonly used frames, as also seen during the 2009 Influenza A (H1N1) pandemic and Q fever epidemic, are: 1) sensationalism (or "alarming"): used to engage people; 2) self-efficacy (or "coping"): provides information on the symptoms of the disease and how people can protect

themselves; 3) thematic: provides the context of the situation; 4) risk magnitude: informs the public how likely they are to contract a disease; 5) episodic: presents a single specific event related to a given issue and is often based on sensational and emotional appeal; 6) uncertainty: states what is unknown thus giving the impression of transparency of information; 7) economic: provides benefits and consequences of an event; 8) responsibility: states who or what is responsible for different actions to resolve the situation, and 9) human interest: uses individual stories to discuss an event, such as an infected case [17-20]. Media often adopt the frames that their resources (such as experts or public health authorities) offer, but journalists also adapt and develop frames [21].

A number of studies have analysed the media reporting of the 2009 A (H1N1) pandemic, analysing the amount of media attention, the content of messages, and message framing used [17,21-29]. A review of Klemm, Hartmann, and Das reported that the 2009 Influenza A (H1N1) pandemic received immense media attention particularly at the start of the pandemic, focused on threat/alarming information, and was rather event-orientated/episodic [30]. Vasterman and Ruigrok (2013) conducted a content analysis of newspaper and television coverage of the pandemic in the Netherlands [21]. They described that the news coverage mainly consisted of alarming messages (74%), focusing in the early stage (24 April - 9 May, 2009) on the expected high number of (fatal) cases and in the third stage (24 October - 28 December, 2009) on the increase in the number of children hospitalized and the death of three healthy children. However, they concluded that the media were generally not more alarming than their sources (i.e. experts and public health authorities).

A few studies described the interaction between message framing and behavioural responses of the public. Chang (2012) conducted a content analysis of Taiwanese newspapers and described that alarm frames were more often used than coping frames [22]. They concluded that alarm frames are likely to result in greater fear and increases in perceived severity and vulnerability, but do not help to develop perceived prevention and treatment efficacy. A study of Sandell, Sebar, and Harris (2013) affirmed the association between message framing in the media and public preventive behaviour [17]. They conducted a qualitative media analysis in Australia and Sweden, aimed at comparing the differences between both countries in how the media framed the messages during the pandemic and in the association between public risk perception and vaccination uptake (vaccination uptake in Australia was 18% and Sweden 60%). They described differences in how the media framed the messages; in Australia responsibility was predominantly reported negatively, preventive measures were limitedly reported on, whereas in the Swedish media responsibility was placed on the community to help protect public health and there was transparency about the uncertainties of the pandemic.

Although trends over time in risk perception and behaviour of the general public during outbreaks of emerging infectious diseases are generally in line with the course and severity of the outbreak, the amount of media attention, and the way messages are framed in the media also strongly influences public risk perception and behaviour. During the 2009 H1N1 pandemic, media attention was high and mainly consisted of alarming messages [21,30].

9.1.2 Research question 2

What are important regional differences in risk perception and preventive behaviour of the general public during outbreaks of emerging infectious diseases?

Inhabitants of highly affected regions/countries (i.e. areas with high number of cases), generally have higher levels of risk perception and preventive behaviour compared to less affected areas. Regional differences in public perception and behavioural responses are also influenced by other factors, like socio-cultural circumstances or public trust in governmental information.

We conducted a follow-up study on public risk perception and behaviour during the Q fever epidemic *(chapter 6)*. Data collection took place in 2009, 2010, and 2012. Panel members of three regions with different incidences of Q fever were invited to participate in this study. The regions included Noord-Brabant, which had the highest incidence of human Q fever cases, and Utrecht and Limburg, where Q fever had been more recently introduced. Two other provinces with low incidences of human Q fever, Groningen and Friesland, served as control region. Overall, respondents in the high incidence region scored highest on public knowledge, perceived anxiety, actual preventive behaviour (all three surveys), and perceived efficacy of measures (in 2009). Furthermore, perceived consequences of getting Q fever in the coming year were considered most severe by respondents in the high incidence region (in 2010). Comparable regional differences were observed in perceived vulnerability, i.e. higher levels of perceived personal susceptibility (in 2009 and 2012) and the perceived chance of getting an infection in the coming year (in 2010 and 2012) were observed among inhabitants in the high incidence region compared to those living in the low incidence area. These findings are generally in line with the real threat, i.e. the province of Noord-Brabant had a high density of large dairy goat farms, had the first community outbreak of Q fever, and had the most human Q fever cases [8,9].

Furthermore, we performed a systematic literature review to describe differences in risk perception and behaviour between inhabitants of various countries during the 2009 Influenza A (H1N1) pandemic *(chapter 5)*. National differences were, mostly, extracted from those studies that included multiple countries. Marked differences in public perception and behaviour were found during the Influenza A (H1N1) pandemic between inhabitants of various countries. For example, Blank, Bonnelye, Ducastel, and Szucs (2012) included inhabitants of all geographical areas in the US, France, and Germany and of the three largest cities in China and Mexico [31]. They reported that perceived severity of and perceived vulnerability to H1N1 was perceived highest among inhabitants of Mexico and lowest among inhabitants of France and Germany. Self reported H1N1 vaccination rates and intention to get seasonal vaccination next year, were highest in the US and Mexico and lower in the other countries. Steelfisher et al. (2012) conducted interviews among the general public in Argentina, Japan, Mexico, the UK, and the USA [32]. They reported that improved hygiene practice (i.e. covering mouth and nose when sneezing and coughing and more cleaning of home or workspace), facemask use, social distancing, and H1N1 vaccination compliance was highest in Mexico compared to the other countries. These differences are likely due to the fact that the H1N1 pandemic started with outbreaks in Mexico and the US and to differences in H1N1 incidence (which was highest in the WHO

Americas region). Subnational differences in preventive behaviour were also observed. Li, Chapman, Ibuka, Meyers, and Galvani (2012) conducted a follow-up survey among inhabitants of 4 US cities (Milwaukee, New York City, Los Angeles, and Washington, DC) [33]. They reported that the four cities varied significantly in the proportion of participants who complied with vaccination against H1N1 (with highest vaccination rates in Milwaukee and lowest in Washington, DC). Vaccination rates were consistent with H1N1 prevalence by city.

Besides number of cases, regional/(sub)national differences in public risk perception and behavioural responses are also influenced by other factors, like socio-cultural circumstances or public trust in governmental information. In *Chapter 4*, differences between native Dutch and immigrant parents were observed during the vaccination decision-making process; immigrant accepters and decliners more often expressed feelings of doubt and regret about the vaccination decision, more often solicited advice from their social networks, and were more often influenced by this advice. Ethnic differences have also been described in intention to comply and actual preventive behaviour during the H1N1 pandemic. For example, Quinn, Kumar, Freimuth, Kidwell, and Musa (2009), Rubin, Potts, and Michie (2010) and Seale et al. (2010) reported higher intentions to accept H1N1 vaccination in people who were not of Caucasian background [34-36]. Rubin, Potts, and Michie (2010) found that participants from non-White ethnic backgrounds were more likely than White participants to take protective action and to adopt avoidant behaviours [35]. The relatively low H1N1 vaccination rates among children in orthodox Protestant communities in the Netherlands (also known as "the Dutch Bible Belt", an area stretching from the south-west to the north-east of the country) and the recent outbreak of measles in this area is also an example of the influence of socio-cultural circumstances on vaccination compliance [37,38]. Ruijs et al. (2012) conducted a study among orthodox Protestant parents to get more insight in their vaccination decision-making process [39]. They described that for orthodox Protestant parents, religious arguments are dominant in vaccination decision-making, above medical aspects of vaccination (i.e. severity of the disease and benefits of vaccination). They conclude that the provision of medical information is often not decisive for parents with religious objections to vaccination.

Establishing and maintaining public trust is fundamental for effective risk communication. As described in the follow-up study conducted during the 2009 H1N1 pandemic *(chapter 2 and 3)*, the perception that governmental information on H1N1 was reliable was one of the determinants for strong intention to comply with government-advised preventive measures in the near future. As described in *Chapter 4*, among the parents who declined H1N1 vaccination for their child, 16% reported "no trust in the government" as a reason for declining vaccination. The importance of public trust in governmental action and information has also been described in other studies on vaccination uptake among the general public during the H1N1 pandemic [13,40-44]. Van der Weerd, Timmermans, Beaujean, Oudhoff, and van Steenbergen (2011) studied governmental trust in relation with vaccination intention during the 2009 H1N1 pandemic in the Netherlands [13]. They describe that higher levels of public trust in governmental action and information were positively related to an intention to adopt vaccination. Furthermore, they describe that trust in governmental action and governmental information decreased over time, probably due to the conflicting messages in the media regarding the severity of the pandemic.

In conclusion, regional differences in public risk perception and preventive behaviour are mainly due to the differences in severity of the outbreak. However, also other factors like socio-cultural circumstances or public trust in governmental information can have an influence on public risk perception and behaviour during outbreaks of emerging infectious diseases.

9.1.3 Research question 3

What are determinants of preventive behaviour or strong intention to comply with preventive measures?

The most often reported determinants positively associated with preventive behaviour or intention to comply are perceived vulnerability/susceptibility, perceived severity, and perceived efficacy of measures. Fear of side effects or harmful consequences and the belief that the vaccine had not been adequately tested were often reported barriers associated with H1N1 vaccination refusal or lower vaccination intention.

In our studies conducted during the Influenza A (H1N1) pandemic we found that taking one or more preventive measures was associated with high anxiety, high self-efficacy, more agreement with statements on avoidance, paying much attention to media information regarding A (H1N1), and with not having any children in the household *(Chapter 2)*. Taking hygienic measures was associated with high anxiety, belief in efficacy of hygienic measures, paying much attention to media information, finding governmental information to be reliable, and with not having any children in the household *(Chapter 3)*. Having a strong intention to comply with government-advised preventive measures in the future was associated with older age, high perceived severity, high anxiety, high perceived efficacy of measures, high self-efficacy, and finding governmental information to be reliable *(Chapter 2)*. Strong intention to comply with H1N1 vaccination was associated with being male, lower educated, unemployed/retired, not having any children in the household, high perceived severity, high anxiety, belief in efficacy of vaccination, and finding governmental information to be reliable *(Chapter 3)*. Fear of side effects or harmful consequences of vaccination and the belief that the vaccine has not been adequately tested were often reported barriers associated with vaccination refusal or lower vaccination intention. In our study on Lyme disease, a history of tick bites, higher levels of knowledge, and moderate/high levels of worry were significant determinants of checking the skin *(Chapter 8)*. Determinants of wearing protective clothing were being unemployed/retired, higher knowledge levels, higher levels of worry about LD, and higher levels of perceived efficacy of wearing protective clothing.

A number of systematic literature reviews have been performed identifying determinants of intention and actual preventive behaviour during the 2009 H1N1 pandemic. Bish and Michie (2010) conducted a review to identify determinants of three types of protective behaviour during a pandemic; i.e. preventive, avoidant, and management of illness behaviour [45]. They included studies conducted during the SARS epidemic, outbreaks of avian influenza H5N1, and the 2009 H1N1 pandemic. Bish, Yardley, Nicoll, and Michie (2011), Blasi, Aliberti, Mantero, and Centanni (2012), Brien, Kwong, and Buckeridge (2012) and Nguyen, Henningsen, Brehaut, Hoe, and Wilson (2011) conducted reviews to examine determinants associated with H1N1 vaccination intention and actual uptake [46-49].

In the next paragraphs, we will describe these determinants based on findings described in these reviews, with a special focus on demographic and psycho-social determinants of H1N1 vaccination intention and actual vaccination uptake among the general public. Additionally, information is provided on determinants of non-pharmaceutical preventive behaviour (such as hygienic practice and avoidance behaviour) during the H1N1 pandemic, based on the review by Bish and Michie (2010) [45]. The constructs from an integrated model to explain health behaviour which served as the theoretical framework for the studies described in this thesis *(see chapter 1)* will be discussed.

9.1.3.1 Demographic determinants

Evidence for the influence of demographic determinants on H1N1 vaccination intention or actual uptake is mixed. Regarding gender, three studies included in the reviews found that men [41,43,50] and two studies found that women [51,52] were more likely to (intent to) be vaccinated. For age, eight studies found that older people were more likely (to intend) to be vaccinated [41,43,50,52-56], whereas four studies found that younger people were more likely to (intent to) be vaccinated [35,51,55,57]. Eight studies reported on the influence of ethnicity [34-36,43,52,55,56,58], of which six studies reported higher vaccination intention or uptake among ethnic minority groups [34-36,43,52,56]. For other demographic variables, including education, household-related factors, personal health, employment status, and marital status, a clear influence was not observed.

9.1.3.2 Psycho-social determinants

Perceived severity (i.e. belief that influenza H1N1 is a severe disease; could have severe personal or long term consequences) was associated with stronger intention to get vaccinated, as reported in studies conducted in the US [58], UK [53], Greece [50], France [41], Turkey [59], and Australia [51]. Furthermore, a belief that the disease was mild or that too much fuss was being made was related with lower vaccination intentions [35,36,58]. Comparable findings were observed for the influence of perceived severity on non-pharmaceutical preventive behaviour. For example, Rubin, Amlot, Page, and Wessely (2009) found that people who reported high levels of perceived disease severity were more likely to report carrying out hygienic measures and avoidance behaviours [60].

Perceived vulnerability/susceptibility (i.e. perception of likelihood or chance to become personally infected) was also associated with stronger intention to get vaccinated, whereas perceiving oneself to be at low or no risk from catching H1N1 was associated with poor vaccination uptake and low intentions, as reported in studies conducted in the US [58], UK [35,53], France [61], Greece [50], Australia [36], and South Korea [62]. A positive association of perceived vulnerability/susceptibility was also found on taking hygienic measures (i.e. hand washing and disinfecting the home) [60,63].

Perceived response efficacy (i.e. belief that vaccine would protect against / reduce the chance of catching influenza H1N1) was associated with stronger intention to get vaccination and higher uptake, as described in studies conducted in UK [53], Turkey [59], South Korea [62], Malaysia [16] and Australia [36]. Furthermore, a positive association has been found between the perceived efficacy and of non-pharmaceutical behaviours (i.e. hand washing, cleaning surfaces and avoidance behaviours) and actually carrying out these behaviours [60].

The influence of level of knowledge and feelings of anxiety (i.e. concern about contracting H1N1 or worry about H1N1 influenza) on intention or preventive behaviour was less consistently reported. However, Setbon and Raude (2010), Rubin, Potts, and Michie (2010), and Horney, Moore, Davis, and MacDonald (2010) reported a positive association of feelings of anxiety on vaccination intention [35,58,61]. Rubin, Amlot, Page, and Wessely (2009) reported a positive association between knowledge about disease/vaccine and vaccination intention [60].

Only one study analysed the influence of perceived self-efficacy (i.e. belief in own ability to perform the behaviour) and found that those who had greater confidence in their ability to avoid infection were more likely to have performed avoidance behaviour to reduce their risk of developing swine flu [63].

Main barriers associated with lower vaccination intention or actual uptake were concerns about vaccine safety (i.e. fear of side effects/harmful consequences) and the belief that the vaccine had not been adequately tested, as reported in studies conducted in the US [58], France [41], Greece [50], Israel [43], Hong Kong [64], Malaysia [16], and Australia [36,51]. Furthermore, worry about safety and side effects of antiviral medication was also associated with lower intention to take antivirals [34,51].

The association between cues to action (i.e. strategies to activate "readiness") and social influence with vaccination intention and uptake were less consistently reported. Having previously been vaccinated against seasonal influenza was associated with stronger intention and actual vaccination uptake, as reported in studies conducted in the US [34,58], UK [53,54], France [41,61], Australia [36,51], and Hong Kong [64]. Two studies found a positive association between trust in authorities (i.e. government preparedness and handling) and avoidance behaviour and acceptance of antiviral medication [34,60]. Finally, a number of studies found an association between a recommendation or advice from a health professional (for example general practitioner), spouse/family/friend or employer/co-worker and stronger intention to get vaccinated and higher uptake [41,54,55,64].

The most often reported determinants positively associated with preventive behaviour or intention to comply are perceived vulnerability/susceptibility, perceived severity, and perceived efficacy of measures. Fear of side effects or harmful consequences and the belief that the vaccine had not been adequately tested were often reported barriers associated with H1N1 vaccination refusal or lower vaccination intention.

9.2 Conclusion and recommendations

The studies presented in this thesis, together with the findings from the international literature, provide useful information for optimising risk communication during future outbreaks of emerging infectious diseases and for conducting further research. In this paragraph the main conclusions are summarised and recommendations for both risk communication policy and practice and future research are described.

First, although trends over time in risk perception and behaviour of the general public during outbreaks of emerging infectious diseases are generally in line with the course and severity of the outbreak, the amount of media attention and the way messages are framed in the media also strongly influence public risk perception and behaviour. During the 2009 H1N1 pandemic, media attention was high, focused on threat information, and was rather event-orientated [30]. A number of risk communication guidelines and tools already have been developed for communicators, including information how to deal with the media during different phases of an outbreak [65,66]. However, based on experiences during the 2009 H1N1 pandemic these tools and guidelines reveal shortcomings. As described by Abraham (2011) the existing tools and guidelines should be expanded with the integration of more traditional health promotion approaches focusing on behaviour change, development of evidence-based guidance on how to use the internet (in particularly social media), understanding how to build and maintain public trust and how to deal with the socio-cultural complexities regarding disease prevention and control [67].

Second, regional differences in public risk perception and preventive behaviour are mainly due to the differences in severity of the outbreak (i.e. number of new or fatal cases), but other factors like socio-cultural circumstances or public trust in governmental information also have an important influence on public risk perception and behaviour. Risk communication during emerging infectious diseases often involves mass-media communication (using television or newspapers) that reaches a large number of people. However, to reach specific target groups, for example those individuals most at risk of the disease or eligible for vaccination, mass-media communication is insufficient [34,68,69]. For effective risk communication, tailoring information to specific socio-cultural circumstances of specific target groups is important.

Third, most often reported determinants positively associated with preventive behaviour or intention to comply are perceived vulnerability/susceptibility, perceived severity and perceived efficacy of measures. Fear of side effects or harmful consequences and the belief that the vaccine has not been adequately tested were often reported barriers associated with H1N1 vaccination refusal or lower vaccination intention. These determinants were rather consistent between countries.

Based on the studies described in this thesis, additional funding was received from the European Commission within the 7th Framework Programme to start a research project entitled “E-com@eu, Effective communication in outbreak management: development of an evidence-based tool for Europe”. The aim of this project is to develop a package of evidence-based behavioural and communication tools (e.g. e-tools) that can be tailored to individual European countries and to specific target audiences/segments as needed. This project started in 2012 and will be finished in 2016.

Recommendations for risk communication policy:

- *Research on risk perception and behavioural responses of the general public during outbreaks of emerging infectious diseases should be embedded in the existing communication/preparedness and response plans.*
- *Findings of research on public perception and behaviour and of other fields of science (i.e. communication/media analyses, sociology, cultural anthropology) should be better integrated with the existing risk communication guidelines/tools.*

Recommendations for risk communication practice:

- *Risk communicators should be aware of the way they present their message in the media. Messages should preferably include actual information on the number of (fatal) cases, chance of becoming infected and the benefits (and safety) of preventive measures.*
- *Risk communication should be tailored to the specific socio-cultural circumstances of the target group.*
- *Establishing and maintaining public trust is fundamental to effective risk communication. To win and maintain public trust it is important to provide up-to-date information about the course of the outbreak including the certainties ("what is known") and uncertainties ("what is unknown"), be open and transparent about decision-making, and take public perception into account.*

Implications for further research:

- *More research is needed on monitoring risk perception and behavioural responses of the general public during outbreaks of emerging infectious diseases. This should include both quantitative (questionnaires) and qualitative (focus group discussions, in-depth interviews) data collection methods.*
- *More (experimental) research is needed on how to translate results of studies on public perception and behaviour into risk communication, how to use social media and how to build, maintain and restore public trust during different outbreak scenarios.*

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Additional file 1

Survey questions 'Risk perception and behavioural responses of the general public during the Influenza A (H1N1) pandemic in the Netherlands'.
We would first ask you to answer some questions about your personal circumstances.

1. What is your country of birth?
- ◯ The Netherlands
- ◯ Dutch Antilles/Aruba
- ◯ Belgium
- ◯ Germany
- ◯ Indonesia
- ◯ Morocco
- ◯ Surinam
- ◯ Turkey
- ◯ Other, namely .....

2. Are you employed at the moment?
- ◯ Yes
- ◯ No

3. What is your marital status?
- ◯ Single
- ◯ Cohabitating
- ◯ Married
- ◯ Divorced
- ◯ Widowed

4. Do you have children (younger than 18 years) in your household?
- ◯ No
- ◯ 1 child
- ◯ 2 children
- ◯ 3-4 children
- ◯ 5 or more children

This survey is about the Mexican flu.

5. Below statements are formulated about the Mexican flu. Please indicate whether the following statements are right or false?

	Right	False	Don't know
The Mexican flu is caused by a new influenza virus	◯	◯	◯
A vaccine is available against the Mexican flu	◯	◯	◯
The Mexican flu can be transmitted by human-to-human contact	◯	◯	◯
People died from the Mexican flu	◯	◯	◯
The Mexican flu can be transmitted through eating pork	◯	◯	◯
Symptoms of the Mexican flu are visible	◯	◯	◯
A flu pandemic occurs once in the 10-50 years	◯	◯	◯

6. How severe do you consider the Mexican flu to be?

◯ Not severe at all
◯ Not severe
◯ Even
◯ Severe
◯ Very severe

7. The Mexican flu is very harmful for my health.

◯ Totally disagree
◯ Mostly disagree
◯ Don't agree or disagree
◯ Mostly agree
◯ Totally agree

8. A number of medical conditions are mentioned below. For each condition, please indicate how awful it would be if you were to be diagnosed with this condition in the next 12 months?

	Not severe at all	Not severe	Even	Severe	Very severe
Seasonal influenza	◯	◯	◯	◯	◯
Diabetes	◯	◯	◯	◯	◯
Heart attack	◯	◯	◯	◯	◯
Mexican flu	◯	◯	◯	◯	◯
HIV or AIDS	◯	◯	◯	◯	◯

9. Do you think that, in general, you are susceptible to get the Mexican flu if you take no preventive measures?

◯ Not at all susceptible
◯ Not really susceptible
◯ Even
◯ Quite susceptible
◯ Very susceptible

10. How likely is it that you will be diagnosed with one of the following medical conditions in the next 12 months?

	Very unlikely	Unlikely	Even	Likely	Very likely
Seasonal influenza	◯	◯	◯	◯	◯
Diabetes	◯	◯	◯	◯	◯
Heart attack	◯	◯	◯	◯	◯
Mexican flu	◯	◯	◯	◯	◯
HIV or AIDS	◯	◯	◯	◯	◯

11. How likely is it that you will be diagnosed with one of the following medical conditions in the next 12 months, compared to others of your sex and age in the Netherlands?

	Much less	Less	Same	More	Much more
Seasonal influenza	◯	◯	◯	◯	◯
Diabetes	◯	◯	◯	◯	◯
Heart attack	◯	◯	◯	◯	◯
Mexican flu	◯	◯	◯	◯	◯
HIV or AIDS	◯	◯	◯	◯	◯

12. Are you worried about the Mexican flu?

◯ Not at all worried
◯ Not worried
◯ A bit worried
◯ Worried
◯ Very worried

13. Are you scared for the Mexican flu?

◯ Not at all scared
◯ Not scared
◯ A bit scared
◯ Scared
◯ Very scared

14. How often do you think about the Mexican flu?

◯ Not at all
◯ A view times
◯ Often
◯ Very often
◯ I could not sleep

15. A number of preventive measures are mentioned below. For each measure, please indicate if you think it will prevent you from getting the Mexican flu.

	Certainly not	Probably not	Even	Probably	Certainly
Keep away from crowded places	○	○	○	○	○
Practice better hygiene (i.e. washing hands more frequent, using tissues when coughing/ sneezing)	○	○	○	○	○
Avoid regions/persons with the flu	○	○	○	○	○
Wear face mask	○	○	○	○	○
Seek medical advice with the onset of symptoms	○	○	○	○	○
Take antiviral medication	○	○	○	○	○
Stay home from school or work	○	○	○	○	○
Get a new vaccine against the Mexican flu	○	○	○	○	○

16. Imagine that health authorities advice these measures. For each measure, please indicate if you think you would be able to take this measure.

	Certainly not	Probably not	Even	Probably	Certainly
Keep away from crowded places	○	○	○	○	○
Practice better hygiene	○	○	○	○	○
Avoid regions/persons with the flu	○	○	○	○	○
Wear face mask	○	○	○	○	○
Seek medical advice with the onset of symptoms	○	○	○	○	○
Take antiviral medication	○	○	○	○	○
Stay home from school or work	○	○	○	○	○
Get a new vaccine against the Mexican flu	○	○	○	○	○

17. Imagine that health authorities advice you to take these measures against the Mexican flu. For each measure, please indicate if you intend to take this measure.

	Certainly not	Probably not	Even	Probably	Certainly
Keep away from crowded places	○	○	○	○	○
Practice better hygiene	○	○	○	○	○
Avoid regions/persons with the flu	○	○	○	○	○
Wear face mask	○	○	○	○	○
Seek medical advice with the onset of symptoms	○	○	○	○	○
Take antiviral medication	○	○	○	○	○
Stay home from school or work	○	○	○	○	○
Get a new vaccine against the Mexican flu	○	○	○	○	○

18. Below are statements formulated, please indicate the degree to which you agree with each of these statements.

	Totally disagree	Mostly disagree	Don't disagree or agree	Mostly agree	Totally agree
There is nothing we can do about it	○	○	○	○	○
The threat is exaggerated by media and government	○	○	○	○	○
I will move to a place without influenza	○	○	○	○	○
I will stock up and stay indoors	○	○	○	○	○
It will not be as bad as predicted	○	○	○	○	○
We will all be completely powerless	○	○	○	○	○

19. What have you done so far to prevent yourself from getting the Mexican flu?

○ Nothing
○ I avoided crowded places
○ I practiced better hygiene (washing hands more frequent, using tissues when coughing or sneezing)
○ I bought a mouth mask
○ I seek medical consultation
○ I avoided persons with influenza like symptoms
○ I bought antiviral medication (as Tamiflu)
○ I got a vaccination against seasonal flu
○ Other, namely .....

20. Have you been vaccinated against seasonal flu during the last winter season (2008-2009)?

○ Yes
○ No
○ Don't know

21. What is the amount of information you received about the Mexican flu?

○ No information
○ A little information
○ Some information
○ Much information
○ Very much information

22. Where did you found the information about the Mexican flu?

○ Newspapers
○ Television
○ Radio
○ Internet
○ Other, namely .....

23. How much attention did you paid to the information about the Mexican flu?

- ◯ Very little
- ◯ Little
- ◯ Even
- ◯ Much
- ◯ Very much

24. Do you consider the information of the government on Mexican flu to be sufficient?

- ◯ Certainly not
- ◯ Probably not
- ◯ Even
- ◯ Probably
- ◯ Certainly

25. Do you consider the information of the government on Mexican flu to be reliable?

- ◯ Certainly not
- ◯ Probably not
- ◯ Even
- ◯ Probably
- ◯ Certainly

26. Which topic would you want to receive more information about?

- ◯ How the infection can be transmitted
- ◯ How the infection can be recognized
- ◯ Which protective measures can be taken to protect myself against infection
- ◯ The likelihood of infection
- ◯ How the infection can be treated
- ◯ Were I can get medication against the Mexican flu
- ◯ Other, namely .....

27. From what source would you like to receive this information? (multiple answers possible)

- ◯ General practitioner
- ◯ Local health institutes (i.e. Municipal Health Service)
- ◯ National health institutes (i.e. National Institute of Public Health and the Environment)
- ◯ Employer
- ◯ Family/friends
- ◯ Don't know
- ◯ Other, namely .....

28. How would you like to receive this information?

- ◯ Newspapers
- ◯ Television
- ◯ Radio
- ◯ Internet
- ◯ Don't know
- ◯ Other, namely .....

This is the end of the survey. Thank you for cooperation. If you have any questions, don't hesitate to contact us.

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Summary

This thesis describes the risk perception and behaviour of the general public during outbreaks of emerging infectious diseases, in particular during the Influenza A (H1N1) pandemic and Q fever epidemic in the Netherlands. The aim is to describe trends over time and regional/(sub)national differences in risk perception and behaviour of the general public, as well as determinants of preventive behaviour.

Chapter 1 describes the definitions of emerging infectious diseases and provides information on outbreaks, symptoms, risk groups, and preventive and treatment measures of influenza, Q fever and Lyme disease. An integrated model to explain health behaviour is described, which includes constructs from both the Health Belief Model and the Protection Motivation Theory. This model forms the theoretical framework for the studies described in this thesis. An overview is provided on studies on risk perception and public preventive behaviour during the Severe Acute Respiratory Syndrome (SARS) epidemic and avian influenza (H5N1) outbreaks, with a focus on trends over time, regional differences and determinants of preventive behaviours or strong intention to comply. The last paragraph of this chapter is directed to risk communication during outbreaks of emerging infectious diseases. Risk communication is defined as an interactive process of exchange of information and opinion on risk among risk assessors, risk managers, and other interested parties. Several guidelines and practical tools have been developed to facilitate risk communication about communicable diseases. Surveillance of perception and behaviour of the public is important and provides useful information for tailoring risk communication and strategies for instructing and motivating the public during outbreaks of infectious diseases. Establishing and maintaining public trust is fundamental for effective risk communication. This chapter concludes with the research questions of this thesis.

1. *What are common patterns in trends over time in risk perception and preventive behaviour of the general public during outbreaks of emerging infectious diseases?*

2. *What are important regional differences in risk perception and preventive behaviour of the general public during outbreaks of emerging infectious diseases?*

3. *What are determinants of preventive behaviour or strong intention to comply with preventive measures?*

Chapter 2 describes the results of a follow-up study (with 3 study rounds) on risk perception and preventive behaviour of the Dutch general public during the 2009 Influenza A (H1N1) pandemic (also known as 'Mexican flu'). Data were collected in April/May (n=456), June (n=478) and August 2009 (n=934) using online questionnaires among adults aged 18 years and older, who were members of an Internet panel (*www.flycatcher.eu*). Between May and August 2009, the level of knowledge regarding Influenza A (H1N1) increased, while perceived severity, perceived self-efficacy, and intention to comply with preventive measures decreased. The perceived reliability of information from the government decreased from May to August 2009. Feelings of anxiety decreased from May

to June, and remained stable afterwards. From June to August 2009, perceived vulnerability increased and more respondents took preventive measures. Taking preventive measures was associated with high levels of anxiety, high perceived self-efficacy, high agreement with statements on avoidance, paying much attention to media information regarding Influenza A (H1N1) and with not having any children in the household. Having a strong intention to comply with government-advised preventive measures in the future was associated with higher age, high perceived severity, high anxiety, high perceived efficacy of measures, high self-efficacy, and finding governmental information to be reliable. The amount of media attention and the way messages were framed in the media during the 2009 H1N1 pandemic, also influenced public risk perception and behaviour.

In addition to Chapter 2, Chapter 3 describes the results of the fourth round of the follow-up study. This survey was conducted in November 2009 (n=754). Perceived severity and feelings of anxiety decreased during the course of the pandemic, while the perceived vulnerability and the percentage of respondents that had taken preventive measures increased. By November 2009, 73% of the respondents had taken measures to prevent Influenza A (H1N1), including washing hands more frequently (61%), using paper tissues more often when coughing and sneezing (34%), and avoiding people with flu symptoms (25%). Determinants of practicing better hygiene were high levels of anxiety, high perceived efficacy of hygienic measures, paying much attention to media information regarding Influenza A (H1N1), finding governmental information to be reliable and not having any children in the household. More than half of the respondents (58%) reported a strong intention to comply with vaccination. Among the respondents with no or low intention to get vaccinated, 40% reported fear of severe side effects as a barrier for vaccination acceptance, 35% reported doubts about effectiveness of the vaccine and 33% a belief that the vaccine was not thoroughly tested. Determinants of strong intention to get vaccinated were being male, lower educated, unemployed/retired, not having any children in the household, having a high perceived severity, a high level of anxiety and a high perceived efficacy of the H1N1 vaccination, and finding governmental information to be reliable.

One of the target groups for vaccination against Influenza A (H1N1) were children aged six months to five years. Chapter 4 describes the vaccination decision making-process of parents who accepted the H1N1 vaccination for their child as well as parents who declined vaccination. Exit interviews were conducted with 1227 parents following the second-dose vaccination round in December 2009. Data on decliners were gathered in June and July 2010 with questionnaires (n=1900); 25 parents participated in in-depth interviews. The most reported reasons for acceptance were “I don’t want my child to become sick” (43%), “Mexican flu can be severe” (10%), “the government advises it, so I do it” (6%), and “if I don’t do it, I will regret it” (6%). The most reported reasons for declining the vaccination were “fear of side effects/harmful consequences” (51%), “just having a bad feeling about it” (46%), and “the vaccine was not thoroughly tested” (39%). Compared to the accepters, parents who declined H1N1 vaccination more often asked advice from their social networks, but less often reported being influenced by this advice. Furthermore, differences between native Dutch and immigrant parents were observed; immigrant accepters and decliners more often expressed feelings of doubt and regret about the vaccination decision, more often solicited advice from their social networks, and were more often influenced by this advice compared to the native Dutch parents.

Chapter 5 describes a systematic literature review on risk perception and preventive behaviour of the general public during the Influenza A (H1N1) pandemic with a focus on trends over time and regional differences. Using online search terms in PubMed, Embase and PsychInfo about 5,500 articles were screened of which 70 met the inclusion criteria. Public misconceptions were apparent regarding modes of transmission and preventive measures. Perceptions and behaviours evolved during the pandemic. In most countries, perceived vulnerability increased, but perceived severity, levels of anxiety, perceived self-efficacy and vaccination intention decreased. Improved hygienic practice and social distancing (i.e. avoiding crowded places) was practiced most commonly. However, vaccination acceptance remained low. Marked regional differences were noted; inhabitants of highly affected regions/countries (i.e. areas with high number of cases) reported higher levels of perceived severity, perceived vulnerability and preventive behaviour compared with inhabitants of less affected areas.

Chapter 6 describes the results of a follow-up study (in 2009, 2010 and 2012) on public risk perception and preventive behaviour during the Q fever epidemic in the Netherlands, with a special focus on trends over time and regional differences. Data were collected in 2009 (n=1347), 2010 (n=1249) and 2012 (n=1030) using online questionnaires among adults aged 18 years and older, who were members of an Internet panel. Panel members of three regions with different incidences of Q fever were invited to participate in this study. The regions included Noord-Brabant, which had the highest incidence of human Q fever, and Utrecht and Limburg, where Q fever had been more recently introduced. Two other provinces with low incidences of human Q fever, Groningen and Friesland, served as control regions. Between 2009 and 2010, we found increases in public knowledge regarding Q fever, perceived severity, anxiety, and perceived efficacy of Q fever preventive measures. In the same period, increases were also observed in actual preventive behaviour, the amount of information received and the attention paid to the information. Between 2010 and 2012, decreasing trends were observed in public knowledge, perceived anxiety, preventive behaviour, amount of information received, and attention paid to the information on Q fever. In 2009, 2010 and 2012 respondents in the high incidence region reported the highest level of knowledge regarding Q fever, perceived anxiety, preventive behaviour, amount of information received, and attention paid to the information.

One of the target groups for vaccination against Q fever were patients with specific cardiovascular conditions and patients with aortic aneurysms or vascular prostheses that lived in high-risk areas. Chapter 7 describes the vaccination decision-making process of patients who accepted Q fever vaccination. A total of 413 patients participated in exit interviews in the period January till April 2011. The most frequently reported reasons for accepting Q fever vaccination were: “I am at an increased risk for developing (chronic) Q fever” (69%); “my general practitioner recommends Q fever vaccination for me” (34%); and “Q fever can be severe (resulting in hospitalizations/deaths/chronic symptoms)” (14%). One-third of the respondents had doubts about being vaccinated against Q fever. These doubts were mostly related to “fear of severe side effects (in the longer term)” (20%); “fear of mild side effects (i.e. local adverse events and/or mild systemic symptoms)” (19%); “practical barriers” (19%; 24/130), and “vaccine has not been thoroughly tested” (10%). Of all respondents, 22% took preventive measures in addition to getting vaccinated; of these, 74% avoided contact with goats and sheep and 36% cancelled or postponed a visit to Q fever-affected areas.

Chapter 8 describes the results of a questionnaire survey on risk perception and behaviour of the general public in the Netherlands regarding Lyme disease. Data collection took place in 2010 using online questionnaires among adults aged 18 years and older, who were members of an Internet panel. Thirty-seven percent of the respondents reported wearing protective clothing when going into nature areas and 32% reported checking their skin after they had been outdoors. A minority (6%) reported to use insect repellent skin products. Main motivators and barriers for performing these three behaviours are described. Determinants of wearing protective clothing were being unemployed/retired, higher knowledge levels, higher levels of worry about Lyme disease and higher levels of perceived efficacy of wearing protective clothing. History of tick bites, higher levels of knowledge and moderate/high levels of worry were determinants of checking the skin.

In chapter 9 the three research questions are answered by summarising the main findings of the studies described in this thesis and discussing the findings in relation to the international literature.

Three main conclusions are described:

1. Although trends over time in risk perception and behaviour of the general public during outbreaks of emerging infectious diseases are generally in line with the course and severity of the outbreak, the amount of media attention and the way messages are framed in the media also strongly influences public risk perception and behaviour;

2. Regional differences in public risk perception and preventive behaviour are mainly due to the differences in severity of the outbreak (i.e. number of new or fatal cases), but also other factors like socio-cultural circumstances or public trust in governmental information can have an influence on public risk perception and behaviour during outbreaks of emerging infectious diseases;

3. The most often reported determinants positively associated with preventive behaviour or intention to comply are perceived vulnerability/susceptibility, perceived severity and perceived efficacy of measures. Evidence for the influence of demographic determinants on vaccination behaviour or intention is mixed. Fear of side effect or harmful consequences of vaccination were often reported barriers associated with vaccination refusal of lower vaccination intention.

This chapter ends with recommendations for optimising risk communication during future emerging infectious disease outbreaks and implication for further research.

For risk communication policy the recommendation is that research on risk perception and behavioural responses of the general public during outbreaks of emerging infectious diseases should be embedded in the existing communication/preparedness and response plans.

More integration of the results of research into risk perception and public behaviour in existing risk communication guidelines/tools is recommended. Also studies in other

fields like communication/media analyses, sociology and cultural anthropology might provide useful information for optimising risk communication in preparation of future outbreaks.

For risk communication practice our recommendations focus on the framing of messages, tailoring risk communication to the specific (socio-cultural) circumstances of target groups, and establishing and maintaining public trust before, during and after an outbreak.

For future research it is recommended to continue monitoring public risk perception and behavioural responses, not only to keep insight in cognitive processes, but also to gain more information on the influence of other factors. Lastly, more (experimental) research is recommended on how to translate results of studies on public perception and behaviour into risk communication and how to build, maintain and restore public trust during different outbreak scenarios.

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Samenvatting

Dit proefschrift beschrijft de risicoperceptie en het gedrag van het publiek bij uitbraken van opkomende infectieziekten, in het bijzonder tijdens de Influenza A (H1N1) pandemie en Q-koorts epidemie in Nederland. Doel van dit proefschrift is het beschrijven van trends over de tijd en regionale verschillen in risicoperceptie en gedrag van het publiek en determinanten van preventief gedrag.

Hoofdstuk 1 beschrijft de definities van opkomende infectieziekten, uitbraken, symptomen, risicogroepen, preventie- en behandelingsmogelijkheden van influenza, Q-koorts en de ziekte van Lyme. Daarnaast wordt een integraal model voor het voorspellen van gezondheidsgedrag beschreven, bestaande uit constructen van het Health Belief Model en de Protectie Motivatie Theorie. Dit model vormt het theoretische kader voor de studies beschreven in dit proefschrift. Daarna volgt een samenvatting van studies naar risicoperceptie en gedrag van het publiek tijdens de Severe Acute Respiratory Syndrome (SARS) epidemie en vogelgriep (H5N1) uitbraken, met specifieke aandacht voor trends over de tijd en regionale verschillen in risicoperceptie en gedrag van het publiek en determinanten van preventief gedrag. Tot slot gaat dit hoofdstuk in op de risicocommunicatie tijdens infectieziekte-uitbraken. Risicocommunicatie wordt gedefinieerd als een interactief proces van het uitwisselen van informatie en meningen over risico's onder professionals en andere geïnteresseerde partijen. Daarnaast is risicocommunicatie gericht op het informeren en stimuleren van het publiek om preventieve maatregelen op te volgen. Er zijn verschillende richtlijnen en tools ontwikkeld om risicocommunicatie te faciliteren. In de risicocommunicatie is het van belang in te spelen en aan te sluiten bij de perceptie van het publiek. Het opbouwen van publiek vertrouwen staat centraal in de risicocommunicatie tijdens infectieziekte-uitbraken. Dit hoofdstuk besluit met de onderzoeksvragen die in dit proefschrift centraal staan.

1. *Wat zijn algemene patronen in trends over de tijd in risicoperceptie en gedrag van het publiek tijdens uitbraken van opkomende infectieziekten?*

2. *Wat zijn belangrijke regionale verschillen in risicoperceptie en gedrag van het publiek tijdens uitbraken van opkomende infectieziekten?*

3. *Wat zijn determinanten van preventief gedrag dan wel determinanten van hoge bereidheid om geadviseerde maatregelen op te volgen?*

Hoofdstuk 2 beschrijft de resultaten van een follow-up studie (bestaande uit 3 rondes) naar de risicoperceptie en het preventieve gedrag van het Nederlands publiek tijdens de 2009 Influenza A (H1N1) pandemie (in de volksmond ook wel 'Mexicaanse griep' genoemd). Data werden verzameld in april/mei (n=456), juni (n=478) en augustus 2009 (n=934). Dit vond plaats middels onlinevragenlijsten onder volwassen van 18 jaar en ouder, die waren aangesloten bij een internetpanel (*www.flycatcher.eu*). De resultaten tonen dat tussen mei en augustus 2009 de kennis over Influenza A (H1N1) onder het publiek toenam, terwijl de ervaren ernst, de ervaren eigen effectiviteit en de intentie om preventieve maatregelen op te volgen afnam. Tevens was er in die periode een afname te zien in het percentage respondenten dat de overheidsinformatie betrouwbaar vond.

Tussen mei en juni 2009 namen de gevoelens van angst af en stabiliseerden daarna. Tussen juni en augustus 2009 nam de ervaren vatbaarheid en het aantal respondenten dat preventieve maatregelen had genomen toe. Preventieve maatregelen werden vaker genomen door respondenten die angstig waren voor Influenza A (H1N1), die geloof hadden in eigen kunnen (eigen effectiviteit), vaker instemden met 'avoidance-statements', veel aandacht hadden besteed aan de media-informatie en zonder thuiswonende kinderen. Hoge bereidheid om overheidsmaatregelen in de toekomst op te volgen bleek aanwezig bij oudere respondenten, die Influenza A (H1N1) als ernstig beschouwden, die angstig waren voor deze griep, die geloof hadden in de effectiviteit van de maatregelen en eigen kunnen en die de overheidsinformatie betrouwbaar vonden. De mate van media aandacht en de manier waarop de berichten tijdens de grieppandemie in de media zijn weergegeven, heeft de perceptie en het preventieve gedrag van het publiek ook beïnvloed.

Als vervolg op hoofdstuk 2 beschrijft hoofdstuk 3 de resultaten van de vierde ronde van de follow-up studie. Deze meting vond plaats in november 2009 (n=754). Ervaren ernst en gevoelens van angst namen af gedurende de pandemie, terwijl de ervaren vatbaarheid en het percentage respondenten dat preventieve maatregelen had genomen toenam. Van de respondenten had 73% maatregelen genomen om de ziekte te voorkomen. Dit betrof voornamelijk vaker handen wassen (61%), vaker papieren zakdoekjes gebruiken bij hoesten en niezen (34%) en vermijden van mensen met griepklachten (25%). Hygiënemaatregelen werden vaker genomen door mensen die angstig waren voor Influenza A (H1N1), die geloofden in de effectiviteit van hygiënemaatregelen, die veel aandacht hadden besteed aan de media-informatie, die de overheidsinformatie betrouwbaar vonden en zonder thuiswonende kinderen. Ruim de helft (58%) van de respondenten gaf aan zich te laten vaccineren tegen Influenza A (H1N1) als zij daarvoor in aanmerking zouden komen. Van de overige respondenten gaf 40% aan bang te zijn voor ernstige bijwerkingen, 35% twijfelde over de effectiviteit van het vaccin en 33% vond het vaccin niet grondig getest. Hoge vaccinatiebereidheid bleek aanwezig bij mannen, lager opgeleiden, mensen zonder baan, mensen zonder thuiswonende kinderen, mensen die de Influenza A (H1N1) als ernstig beschouwden, die angstig waren voor deze griep, die geloofden in de effectiviteit van de vaccinatie en die de informatie van de overheid betrouwbaar vonden.

Eén van de doelgroepen voor de vaccinatie tegen Influenza A (H1N1) waren kinderen in de leeftijd van zes maanden tot vijf jaar. Hoofdstuk 4 beschrijft het vaccinatiebesluit-vormingsproces van ouders die hun kind lieten vaccineren evenals ouders die vaccinatie voor hun kind weigerden. In december 2009 werden exitinterviews gehouden met 1227 ouders die vaccinatie accepteerden. Daarnaast vulden 1900 vaccinatieweigeraars in juni en juli 2010 een vragenlijst in; 25 van hen namen tevens deel aan een diepte-interview. De belangrijkste redenen voor vaccinatieacceptatie waren: "ik wil niet dat mijn kind ziek wordt" (43%), "deze griep kan ernstig zijn (ziekenhuisopnames/doden)" (10%), "de overheid adviseert het, dus doe ik het" (6%) en "als ik het niet doe, krijg ik later misschien spijt" (6%). De belangrijkste redenen voor het weigeren van de vaccinatie waren: "angst voor bijwerkingen/schadelijke gevolgen" (51%), "er een slecht gevoel over te hebben" (46%) en "het vaccin is niet grondig getest" (39%). Vergeleken met de ouders die vaccinatie accepteerden, vroegen vaccinatieweigeraars vaker advies aan hun sociale omgeving, maar lieten zich minder vaak beïnvloeden door dit advies. Daarnaast waren

er verschillen tussen autochtone en allochtone ouders; allochtone ouders rapporteerden vaker gevoelens van twijfel en spijt ten aanzien van het vaccinatiebesluit, vroegen hun sociale omgeving vaker om advies en werden hier meer door beïnvloed vergeleken met de autochtone ouders.

Hoofdstuk 5 beschrijft een systematisch literatuuronderzoek naar de risicoperceptie en het preventieve gedrag van het publiek tijdens de Influenza A (H1N1) pandemie met de focus op trends over de tijd en internationale/regionale verschillen. Met behulp van onlinezoektermen in PubMed, Embase en PsychINFO werden ongeveer 5500 artikelen gescreend waarvan 70 voldeden aan de inclusiecriteria. Gedurende de pandemie nam in de meeste landen de ervaren vatbaarheid onder het publiek toe, terwijl de ervaren ernst, mate van angst, ervaren eigen effectiviteit en vaccinatieintentie afnamen. Hygiënemaatregelen en 'social distancing' (vermijden van plekken met veel mensen) waren de uitgevoerde preventieve maatregelen die het meest werden gerapporteerd. In veel landen bleef de vaccinatiegraad laag. Regionale verschillen in de perceptie en het preventieve gedrag van het publiek waren aanwezig. Zo ervoeren inwoners van gebieden met veel geïnfecteerde en/of fatale gevallen over het algemeen een hogere mate van ernst en vatbaarheid en namen ze vaker preventieve maatregelen vergeleken met inwoners van gebieden met een lagere incidentie van Influenza A (H1N1).

Hoofdstuk 6 beschrijft de resultaten van een follow-up studie (in 2009, 2010 en 2012) naar de risicoperceptie en het preventieve gedrag tijdens de Q-koorts epidemie in Nederland, met de focus op trends over de tijd en regionale verschillen in risicoperceptie en preventief gedrag. Data werden verzameld in 2009 (n=1347), 2010 (n=1249) en 2012 (n=1030) middels onlinevragenlijsten onder volwassen van 18 jaar en ouder, die waren aangesloten bij het een internetpanel. Inwoners van drie verschillende gebieden werden uitgenodigd deel te nemen: 1) provincie Noord-Brabant, met de hoogste Q-koorts incidentie; 2) provincie Utrecht en Limburg, waar Q-koorts recenter was geïntroduceerd en 3) Groningen en Friesland, twee provincies met minder Q-koorts gevallen. Deze provincies dienden als controle regio's. Tussen 2009 en 2010, nam de kennis van de respondent toe ten aanzien van Q-koorts, evenals de ervaren ernst, mate van angst en ervaren effectiviteit van preventiemaatregelen. Daarnaast steeg het percentage respondenten dat preventieve maatregelen nam, de hoeveelheid ontvangen informatie over Q-koorts en de mate van aandacht besteed aan deze informatie. Tussen 2010 en 2012 daalde de kennis, de ervaren angst, het preventieve gedrag, de hoeveelheid ontvangen informatie over Q-koorts en de aandacht besteed aan deze informatie. In zowel 2009, 2010 als 2012 rapporteerden respondenten in Noord-Brabant vergeleken met de andere regio's meer kennis over Q-koorts en een hogere mate van angst, namen zij vaker preventieve maatregelen, ontvingen meer informatie over Q-koorts en besteedden meer aandacht aan deze informatie.

Hoofdstuk 7 gaat in op het vaccinatiebesluitvormingsproces van patiënten die voor Q-koortsvaccinatie in aanmerking kwamen. Exitinterviews werden gehouden met 413 patiënten die zich hadden laten vaccineren tegen Q-koorts in de periode januari tot en met april 2011. De meestgenoemde redenen voor vaccinatieacceptatie waren: "ik heb een verhoogd risico op het ontwikkelen van (chronische) Q-koorts" (69%), "mijn huisarts heeft mij aangeraden me te laten vaccineren tegen Q-koorts" (34%) en "Q-koorts kan ernstig zijn" (14%). Een derde had getwijfeld voorafgaand aan de vaccinatie; deze twijfels hadden

voornamelijk te maken met de angst voor ernstige bijwerkingen op de langere termijn (20%) en milde bijwerkingen (19%), praktische barrières (19%) en het idee dat het vaccin niet grondig getest was (10%). Van de respondenten had 22% preventieve maatregelen genomen tegen Q-koorts. Hiervan vermeed 74% het contact met geiten en schapen en annuleerde 36% een bezoek aan een Q-koorts besmet gebied.

Hoofdstuk 8 beschrijft de resultaten van een vragenlijstonderzoek naar risicoperceptie en preventief gedrag van het Nederlands publiek ten aanzien van de ziekte van Lyme. Dit vragenlijstonderzoek vond plaats in 2010 middels onlinevragenlijsten onder volwassen van 18 jaar en ouder, die waren aangesloten bij een internetpanel. Van de respondenten gaf 37% aan beschermende kleding te dragen die de huid bedekken (lange mouwen/broeken) als zij de natuur ingingen en 32% gaf aan hun huid regelmatig te controleren op teken. Een minderheid (6%) rapporteerde gebruik van insectenwerende producten als preventieve maatregel. Dit hoofdstuk beschrijft tevens de motiverende en belemmerende factoren voor het nemen van deze drie preventieve maatregelen. Het dragen van beschermende kleding om de ziekte van Lyme te voorkomen, werd vaker gedaan door respondenten zonder baan, die meer kennis hadden en bezorgd waren over de ziekte van Lyme en die geloofden in de effectiviteit van het dragen van beschermende kleding. Controleren van de huid op de aanwezigheid van teken werd vaker gedaan door respondenten die in het verleden al eens door een teek waren gebeten, die meer kennis hadden van teken en/of de ziekte van Lyme en een hoge mate van bezorgdheid rapporteerden over de ziekte van Lyme.

In hoofdstuk 9 worden de drie onderzoeksvragen beantwoord gebaseerd op de belangrijkste bevindingen van de studies beschreven in de voorgaande hoofdstukken. De resultaten worden vergeleken met de internationale literatuur.

De drie belangrijkste conclusies zijn:

1. Trends over de tijd in risicoperceptie en preventief gedrag van het publiek bij uitbraken van opkomende infectieziekten zijn over het algemeen in lijn met het verloop en de ernst van de uitbraak. Echter, de mate van media aandacht en de manier waarop de media de berichten weergeeft heeft ook een sterke invloed op de perceptie en het preventieve gedrag van het publiek;

2. Regionale verschillen in de perceptie en het gedrag van het publiek worden voornamelijk veroorzaakt door verschillen in ernst van de uitbraak (aantal nieuwe of fatale gevallen), maar ook andere factoren zoals sociaal-culturele omstandigheden of het vertrouwen van het publiek in de overheidsinformatie kunnen van invloed zijn;

3. De meest gerapporteerde determinanten die een positief effect hebben op preventief gedrag of op de intentie om preventieve maatregelen op te volgen zijn: ervaren waarschijnlijkheid of kans om zelf geïnfecteerd te raken (ervaren vatbaarheid), geloof dat de ziekte ernstig is of langetermijnconsequenties kan hebben (ervaren ernst) en geloof dat de preventieve maatregel beschermt of de kans op infectie verkleint. Angst voor bijwerkingen of schadelijke gevolgen van vaccinatie was de belangrijke barrière die resulteerde in vaccinatieweigering of lage vaccinatieintentie.

Dit hoofdstuk besluit met een aantal aanbevelingen voor het optimaliseren van de risicocommunicatie bij toekomstige uitbraken van opkomende infectieziekten.

Voor risicocommunicatiebeleid is het een meerwaarde om onderzoek naar perceptie en gedrag van het publiek in te bedden in de bestaande communicatie/preparedness en response plannen. Daarnaast is integratie van resultaten van dergelijk onderzoek en onderzoek op andere wetenschappelijk gebieden (zoals media/communicatie wetenschappen, sociologie, culturele antropologie) in bestaande risicocommunicatierichtlijnen en tools van belang.

Aanbevelingen voor risicocommunicatie in de praktijk richt zich op "framing" van de informatie, het afstemmen van de risicocommunicatie op specifieke (sociaal-culturele) omstandigheden van specifieke doelgroepen en aandacht hebben voor het publiek vertrouwen voor, tijdens en na een infectieziekte-uitbraak.

Ten slotte is meer onderzoek naar de perceptie en het preventieve gedrag van het publiek bij infectieziekte-uitbraken van belang, niet alleen om inzicht te houden in de cognitieve processen maar ook om de invloed van andere factoren in kaart te brengen. Daarnaast is het van belang meer (experimenteel) onderzoek uit te voeren naar de wijze waarop onderzoeksresultaten vertaald kunnen worden naar communicatie in de praktijk en hoe publiek vertrouwen kan worden opgebouwd, behouden en hersteld.

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Dankwoord

Dan is het zover; de data geanalyseerd, (bijna) alle artikelen gepubliceerd, de inleiding en discussie geschreven en wat rest is: het dankwoord! Ik wil graag iedereen bedanken die op één of andere wijze een bijdrage heeft geleverd aan de totstandkoming van dit proefschrift.

Allereerst mijn promotor Jan Hendrik Richardus, co-promotor Hélène Voeten en begeleider/paranimf Desirée Beaujean. Jan Hendrik, ik ben je zeer dankbaar voor de mogelijkheid die jij me hebt gegeven om mijn proefschrift af te ronden. Daarnaast is jouw inhoudelijke commentaar vanuit een 'helicopterview' zeer waardevol geweest voor het verbeteren van de artikelen. Hélène, ik heb jouw begeleiding en onze samenwerking als zeer prettig ervaren en heb veel van je geleerd de afgelopen jaren. Jij gaf mij de ruimte en het vertrouwen om de onderzoeksprojecten zelfstandig uit te voeren en mijzelf als onderzoeker verder te ontwikkelen. Bedankt voor het altijd weer kritische doornemen van alle stukken die ik jou toestuurde. Desirée, we werkten bij het RIVM al samen aan het schrijven van subsidieaanvragen. Daarna heb jij me naar Rotterdam 'geleid' en zijn we intensief blijven samenwerken. Bedankt voor het meefinancieren, meedenken, meewerken, meeschrijven en meeleven! Heel fijn dat jij aan mijn zijde wilt staan tijdens de verdediging van mijn proefschrift.

Ik wil alle co-auteurs van de artikelen opgenomen in dit proefschrift bedanken. Onno de Zwart, Gerjo Kok, Pepijn van Empelen, Jim van Steenbergen, Clementine Wijkmans en Aura Timen, bedankt voor jullie waardevolle bijdrage aan de artikelen. Onno, mijn promotieonderzoek is een vervolg op het risicoperceptie onderzoek dat jij tijdens de SARS epidemie en vogelgriep-uitbraken hebt uitgevoerd. Ik wil dan ook jou en tevens Jan Groot bedanken voor de kans die ik heb gekregen om binnen de afdeling Infectieziektebestrijding van de GGD Rotterdam-Rijnmond aan dit onderzoek te werken.

Medewerkers van het RIVM/LCI en de GGD Hart voor Brabant bedankt voor jullie hulp bij het afnemen van de exitinterviews tijdens de Influenza A (H1N1) vaccinatiecampagne in Ahoy Rotterdam en de Q-koorts vaccinatiecampagne bij de GGD Hart voor Brabant in 's Hertogenbosch. Medewerkers van onderzoeksbureau Flycatcher, in het bijzonder Pleun Aardening en Sanne Neijnens, bedankt voor jullie hulp bij het verzamelen van de data. Ik heb enorme waardering voor jullie betrokkenheid en flexibiliteit. De panelleden en participanten die deel hebben genomen aan één van de onderzoeken vermeld in dit proefschrift, bedankt voor jullie respons!

Alle verpleegkundigen, artsen en het secretariaat van de afdeling Infectieziektebestrijding van de GGD Rotterdam-Rijnmond en collega's van de afdeling Maatschappelijke Gezondheidszorg van het Erasmus MC, bedankt voor jullie bijdrage aan, en interesse in mijn onderzoek en de kritische vragen tijdens de lunchreferaten en research meetings. Caspar Looman, bedankt voor jouw advies bij de statistische analyses. Wichor Bramer, jouw hulp bij de systematische literatuur search was onmisbaar, bedankt!

Mijn naaste collega onderzoekers en beleidsmedewerkers van de GGD Rotterdam-Rijnmond Abby, Anita, Hannelore, Ines, Irene, Jeanelle, Marina, Mariska, Marja, Marijke, Mireille, Pjer, Reinoud, Sarah, Tizza en Ytje, bedankt voor de prettige werksfeer, jullie steun, belangstelling en de gezelligheid voor, tijdens en na het werk. Ik zal jullie zeker missen! Abby,

Mariska en Tizza succes met jullie promotieonderzoeken, houd goede moed en zet ‘m op! Abby, thank you very much for proofreading parts of my thesis. Ytje, bedankt voor de “mama-talks”, we houden contact!

Mireille Broeders, bedankt voor de kans die jij me geeft om me verder te ontwikkelen bij het Radboudumc als postdoc onderzoeker en coördinator van het ‘borstkankerscreening op-maat’ project. Erg fijn dat ik de ruimte krijg om naast mijn werkzaamheden in Nijmegen de onderzoekwerkzaamheden in Rotterdam af te ronden. Ik kijk uit naar onze samenwerking!

De ‘meiden uit Maastricht’, Annemarie, Debbie, Marjon, Nanda en Rachel, waarmee ik een fantastische studententijd heb mogen beleven in Limburg. Nu zijn we ‘uitgevlogen’ en wonen we verder van elkaar, hebben man en (één, twee of drie) kinderen gekregen maar het contact blijft. Dat er nog maar vele onvergetelijke weekendjes weg mogen volgen!
De ‘treinvriendinnen’, Eveline, Femke, Petra, Sandra en Sanela, wat hebben we er al veel uurtjes in de trein en gezellige etentjes opzitten. Wanneer is ons volgende TV-diner? Eveline, Femke en Petra, bedankt voor jullie (taalkundige) correcties! Verder wil ik al mijn vrienden bedanken voor de afleiding, gezelligheid en ontspanning. Ik hoop na mijn promotie wat meer tijd vrij te kunnen maken om jullie te zien.

De medewerkers en leidsters van kinderdagverblijf Sam&Co (locatie Sam&Rikkie en Sam&Koos), bedankt voor de zorg, aandacht en liefde voor Noa en Sep!

Mijn schoonouders, Henny en Bennie, met wie ik het zeer heb getroffen (ik kan het niet vaak genoeg zeggen) wil ik bedanken voor het vele oppassen, de heerlijke maaltijden en de hulp in de huishouding. Gaan we nog eens fietsen langs de Moezel? Laura en Martijn, ik geniet als ik zie hoe onze kinderen zich zo goed met elkaar kunnen vermaken!

Het opgroeien in een gebroken gezin heeft naast de mindere momenten ook een positieve invloed op mij gehad. Hiervoor ben ik mijn moeder, vader en broer zeer dankbaar.
Ma en Leo, bedankt voor jullie vertrouwen, hulp en steun de afgelopen jaren. Mam, mede dankzij jou heb ik de juiste (studie)keuzes gemaakt en ben ik geworden wie ik nu ben.
Pa en Gerri, bedankt voor jullie interesse en betrokkenheid bij mijn werk en gezin.
Lieve Mark, ik ben trots op jou als ik zie wat jij samen met Chanouke hebt bereikt. Bedankt voor de fijne momenten samen!

En als laatste wil ik mijn gezin bedanken. Noa en Sep, wat is het genieten om jullie mama te zijn en jullie te zien ontwikkelen tot lieve, sociale, zelfstandige (en soms een beetje ondeugende) kinderen. Wat is het heerlijk om thuis te komen, de hectiek van het promoveren achter me te laten om even lekker te knuffelen, kletsen en knutselen.
Paulo, wat ben ik trots op ons! Jij bent niet alleen mijn levenspartner en sportmaatje maar ook een fantastische papa voor onze kinderen. Daarnaast was je de afgelopen jaren ook mijn ICT-adviseur (als de computer weer eens niet deed wat ik wilde) en personal assistant (als ik het overzicht even kwijt was). Ook tijdens de verdediging van mijn proefschrift zal jij aan mijn zijde staan. In 2012 heb je mij op het strand op Curaçao ten huwelijk gevraagd, zullen we ons nu eindelijk in het echt verbinden door te trouwen?

Deventer, Augustus 2013.

Curriculum vitae

Marloes Bults werd in 1982 geboren in Markelo (Hof van Twente). Na het behalen van haar HAVO diploma in 1999 aan de openbare scholengemeenschap de Waerdenborch te Holten, volgde zij de HBO opleiding Verpleegkunde aan de Saxion Hogeschool te Enschede waar zij in 2003 afstudeerde. In datzelfde jaar ging zij Gezondheidswetenschappen studeren aan de Universiteit van Maastricht (afstudeerrichting Gezondheidsvoorlichting – GVO). In het kader van deze opleiding deed zij literatuuronderzoek naar de invloed van leefstijl op de risicoperceptie ten aanzien van hart- en vaatziekten onder adolescenten. Als afstudeeropdracht voerde zij een kwantitatief onderzoek uit naar de kwaliteit van de patiëntenvoorlichting binnen het Thoraxcentrum Twente te Enschede.

Na het afronden van haar studie, begon zij in 2006 als beleidsmedewerker met onderzoekstaken bij het Rijksinstituut voor Volksgezondheid en Milieu (RIVM) te Bilthoven. Eind 2008 maakte Marloes de overstap van het RIVM naar de GGD Rotterdam-Rijnmond, afdeling Infectieziektebestrijding. Van 2008 tot en met 2010 werkte zij aan een ZonMw onderzoeksproject naar risicoperceptie van infectieziekten. In het kader van dit project werd een instrument (vragenlijst) ontwikkeld om risicoperceptie en gedrag van het publiek te meten. Deze vragenlijst is ingezet tijdens de Influenza A (H1N1) pandemie en de Q-koorts epidemie in Nederland. In 2010 werd aanvullende subsidie verkregen om meer inzicht te krijgen in het vaccinatiebesluitvormingsproces van ouders die de Influenza A (H1N1) vaccinatie voor hun kind weigerden. Om haar promotieonderzoek af te ronden is Marloes sinds 2011 in dienst van het Erasmus MC, Universitair Medisch Centrum Rotterdam, afdeling Maatschappelijke Gezondheidszorg. Hier werkt zij aan een Europees onderzoeksproject genaamd E-com@eu, Effective Communication in Outbreak Management: development of an evidence-based tool for Europe. In het kader van dit project heeft zij een systematische literatuur review uitgevoerd naar de risicoperceptie en het preventieve gedrag van het publiek tijdens de Influenza A (H1N1) pandemie.

Sinds september 2013 is Marloes werkzaam als postdoc onderzoeker bij het Radboud universitair medisch centrum te Nijmegen. Bij de afdeling Health Evidence werkt zij binnen de onderzoekslijn borstkankerscreening als coördinator op het project ‘Breast cancer screening – from one-size-fits-all to a personalised risk-based approach’.

Marloes is verloofd met Paulo ten Buuren en moeder van Noa en Sep.

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Bults M, Beaujean DJMA, Richardus JH, Voeten HACM. Perceptions and behavioral responses of the general public during the 2009 Influenza A (H1N1) pandemic: a systematic review. Submitted for publication.

Bults M, Beaujean DJMA, Wijkmans CJ, Richardus JH, Voeten HACM. Q fever in the Netherlands: public perceptions and behavioural responses in three different epidemiological regions: a follow-up study. Submitted for publication

Beaujean DJMA, **Bults M**, van Steenbergen JE, Voeten HACM. Study on public perceptions and protective behaviours regarding Lyme disease among the general public in the Netherlands: implications for prevention programs. BMC Public Health 2013;13:225

Bults M, Beaujean DJMA, Wijkmans CJ, Timen A, Richardus JH, Voeten HACM. Why did patients with cardiovascular disease in the Netherlands accept Q fever vaccination? Vaccine 2012;30:3369-3375.

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Bults M, Beaujean DJMA, Wijkmans CJ, Timen A, Richardus JH, Voeten HACM. Q-koortsvaccinatie van hoogrisicopatiënten. Infectieziekten Bulletin – themanummer; okt. 2012.

Bults M, Beaujean DJMA, de Zwart O, Kok G, van Empelen P, van Steenbergen JE, Richardus JH, Voeten HACM. Mexicaanse griep: risicoperceptie bij de bevolking, eigen maatregelen en vertrouwen in overheidsinformatie. Infectieziekten Bulletin 2010;21(8):288-292.

PhD portfolio summary
Summary of PhD training and teaching activities

Name PhD student: Marloes Bults
Erasmus MC, University Medical Center Rotterdam Department: Public Health

PhD period: 2009 - 2013
Promotor(s): Prof. dr. J.H. Richardus
Supervisor: dr. H.A.C.M. Voeten

1. PhD training	Year	Workload (Hours/ECTS)
Research skills and in-depth courses		
PCDI Postdoc Retreat - Life Sciences (3 day course)	2013	0.5 ECTS
Several courses including Kwalitan, Excel Advanced, Time management	2009-2012	2.5 ECTS
Training Endnote	2011	8 hours
Training Social Marketing (1 day course)	2010	8 hours
Training Regression Analysis for Clinicians, NIHES (4 day course)	2010	1.9 ECTS
Presentations		
Dutch Congres Public Health, Rotterdam, 9 April 2009; poster presentation "Risk perception of infectious diseases: implication for infectious disease control"	2009	0.5 ECTS
Municipal Public Health Service Rotterdam-Rijnmond, Rotterdam, 14 April 2009; oral presentation "Preventive behaviour of the general public during outbreaks of infectious diseases – Recommendations for risk communication"	2009	1 ECTS
Infectious Disease Control Expert Meeting (LOI), 19 April 2009; oral presentation "Preventive behaviour of the general public during outbreaks of infectious diseases – Recommendations for risk communication"	2009	0.5 ECTS
National Institute of Public Health, Symposium 'Help, a crisis', Bilthoven, 9 October 2009; oral presentation "Public risk perception and behaviour during outbreaks of emerging infectious diseases"	2009	1 ECTS
Dutch Congres Public Health, Amsterdam, 7 April 2011; oral presentation "Vaccination campaign against Influenza A (H1N1): vaccination decision-making process of parents?"	2011	1 ECTS
Research meeting, Erasmus MC, Rotterdam, 21 May 2011, oral presentation "Risk perception and behavioural responses during outbreaks diseases"	2011	0.5 ECTS
Infectious Disease Control Expert Meeting (RAC), Bilthoven, 10 june 2011; oral presentation "Outbreaks of infectious diseases: public risk perception and behaviour"	2011	0.5 ECTS
Infectious Disease Control Expert Meeting (LOI), Utrecht, 13 September 2011; oral presentation "Outbreaks of infectious diseases: public risk perception and behaviour"	2011	0.5 ECTS
Municipal Public Health Service Hart voor Brabant, 's Hertogenbosch, 17 November 2011; oral presentation "Q fever: public risk perception"	2011	1 ECTS
Infectious Disease Control Expert Meeting (LOVI), Bilthoven, 22 November 2011; oral presentation "De ISI onderzocht: verbeterpunten na toetsing aan gebruikers"	2011	0.5 ECTS

ERASMUS UNIVERSITEIT ROTTERDAM

1. PhD training	Year	Workload (Hours/ECTS)
Kick-off meeting E-com@eu, Amsterdam, 20&21 March 2012; oral presentation "WP4: Vaccination knowledge, attitudes, risk perception & vaccination non-response"	2012	1 ECTS
Research meeting, Erasmus MC, Rotterdam, 21 May 2012; oral presentation "Public risk perception and behavioural responses during outbreaks of infectious diseases"	2012	1 ECTS
Dutch Congres Public Health, Amsterdam, 12 April 2012; poster presentation "Q fever vaccination: insight in vaccination decision-making process"	2012	0.5 ECTS
E-com@eu meeting, Münster, 22&23 January 2013; oral presentation "WP4: Vaccination knowledge, attitudes, risk perception & vaccination non-response (update)"	2013	1 ECTS
Municipal Public Health Service Rotterdam-Rijnmond, lunchmeeting AIO's/ OIO's, 21 February 2013; oral preseltation "Public risk perception and behavioural responses during outbreaks of infectious diseases	2013	0.5 ECTS
23e Transmissiedag, Amersfoort, 19 March 2013, poster presentation "Q fever vaccination: insight in vaccination decision-making process"	2013	0.5 ECTS
Dutch Congres Public Health, Ede, 4 April 2013; oral presentation "Outbreaks of emerging infectious diseases: public risk perception and preventive behaviour"	2013	1 ECTS
Seminars and workshops		
VWS meeting/workshop - Capaciteiten-analyse grieppandemie 3+21 February 2012, The Hague	2012	1 ECTS
Erasmus University Medical Centre – Seminars, meetings MGZ, Rotterdam	2009-2013	1 ECTS
Dutch Congres Public Health – Workshops, 2009, 2011-2013	2009, 2011-2013	2.5 ECTS
2. Teaching activities		
Supervising master student	2009-2010	1 ECTS
Supervising research assistent	2013	2 ECTS
Reviewer BMC Public Health, BMC Infectious Diseases, Journal of Pediatric Infectious Diseases, Journal of Behavioural Medicine	2009-2013	2 ECTS
Consultant on risk perception research for other MPHS/institutes	2009-2013	2 ECTS

Marloes Bults was born in Markelo (Hof van Twente) in 1982. After completing her secondary education at the Waerdenborch Holten in 1999, she followed the education for nursing care professionals at the Saxion in Enschede where she graduated in 2003. In the same year she started to study Health Sciences (specialisation Health Education and Promotion) at the University of Maastricht. As part of her study she conducted a literature study on the effect of lifestyle on the risk perception of heart- and vascular diseases among adolescents. During the final year she conducted a quantitative study on the quality of patient information at the Thorax Centre Twente in Enschede.

After graduating, she started in 2006 as policy officer with a focus on research at the National Institute for Public Health and the Environment (RIVM) in Bilthoven. In 2008, she started working for the Division of Infectious Diseases Control at the Municipal Public Health Service Rotterdam-Rijnmond. From 2008 to 2010 she worked on a ZonMw project on public risk perception of infectious diseases. A tool (questionnaire) was developed to measure risk perception and behaviour of the general public. This questionnaire was used during the Influenza A (H1N1) pandemic and Q fever epidemic in the Netherlands. In 2010, additional funding was obtained to get more insight in the vaccination decision making process of parents who declined H1N1 vaccination for their child. Since 2011, Marloes is employed at the Erasmus MC, University Medical Center Rotterdam, Department of Public Health, to finish her PhD project and work on a European research project. This project is entitled E-com@eu, Effective Communication in Outbreak Management: development of an evidence-based tool for Europe. As part of this project she conducted a systematic literature review on public risk perception and behaviour during the Influenza A (H1N1) pandemic.

Since September 2013, Marloes is working as a postdoc researcher at the Radboud university medical center in Nijmegen. At the department of Health Evidence she is involved in research on breast cancer screening and works as a coordinator on the project ‘Breast cancer screening: from one-size-fits-all to a personalised risk-based approach’.