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## **TECHNICAL** REPORT

# A literature review on effective risk communication for the prevention and control of communicable diseases in Europe

Insights into health communication

**ECDC** TECHNICAL REPORT

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Insights into health communication



This literature review was commissioned by the European Centre for Disease Prevention and Control (ECDC) as one of the outputs of the Framework Partnership Agreement Grant /2009/007 'Establishing a programme for dissemination of evidence-based health communication activities and innovations on communicable diseases for country support in the EU and EEA/EFTA, 2009–12', with a consortium of universities comprised of the Health Promotion Research Centre at the National University of Ireland Galway, as the lead coordinating centre, and the Institute for Social Marketing, University of Stirling, Scotland, and the University of Navarra Clinic, Pamplona, Spain.

The literature review was produced by Jennifer J. Infanti, Jane Sixsmith, Margaret M. Barry, Health Promotion Research Centre, National University of Ireland Galway and Jorge M. Núñez-Córdoba, Cristina Oroviogicoechea-Ortega, Francisco Guillén-Grima, University of Navarra Clinic, Pamplona, Spain.

The project was overseen by Ülla-Karin Nurm, Andrea Würz, Piotr Wysocki and Irina Dinca, Public Health Development Section, Public Health Capacity and Communication Unit, ECDC.

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## Executive summary

This review examines the current body of literature on risk communication related to communicable diseases, focusing on: (i) definitions and theories of risk communication; (ii) methodologies, tools and guidelines for risk communication research, policy and implementation; and (iii) implications, insights and key lessons learned from the application of risk communication principles in real-world settings.

Effective risk communication is essential to limiting morbidity and mortality caused by communicable diseases, in addition to minimising the damage that communicable diseases can cause to national economies and public health infrastructure. The aim of the review was thus to uncover the general principles of effective risk communication that can assist with the prevention and control of communicable diseases in the European context, as well as specific examples of good practice that can be built on in future risk communication policies, guidance, research and implementation scenarios. The review brings together the current body of literature on risk communication on communicable diseases in a concise reference document that can be used to inform the development of evidence-based risk communication strategies and approaches.

To conduct the review, various databases were searched to locate published academic literature on the topic of risk communication for communicable diseases. In addition, both general and targeted internet searches were undertaken to locate relevant unpublished literature on the topic, such as conference presentations, reports and other technical documents. The literature search prioritised documents produced over the past ten years and relevant to the European context. Following the collection of relevant literature, key themes were identified and analysed and findings synthesised for the production of this report.

The review revealed that the multi-cultural and multi-lingual environment of Europe presents a unique set of challenges to effective risk communication on communicable diseases to which the most promising solutions include: (i) collaboration of an international coordinating body with both national and local non-governmental organisations; and (ii) focusing on the development of cross-sectoral and cross-national risk preparedness, surveillance, response and monitoring strategies in the region. In addition, both quantitative and qualitative studies on risk communication have brought valuable insights to light on the topic, but there is an important need for evaluation research to better understand the effectiveness of risk communication as it unfolds during real-life events.

In terms of risk communication practice, there are various resources available to risk communicators today (for example, toolkits, training modules, guidance frameworks), but when tested, challenges, gaps and limitations have been exposed. The review indicates that risk communication resources need to be continuously updated to meet new and developing needs (for example, strategies for effective web-based and social networking communication are notably absent yet highly relevant in today's world); and the scope of the resources must be broadened beyond the current focus on risk communication in the context of emergency and outbreak situations.

Other principal conclusions of the review are that risk communication messages often fail to reach the intended communities, including those people most at risk of the disease. Similarly, despite the availability of planning tools and pre-crisis event and readiness efforts, many countries in the European region still need to concentrate on advanced risk communication planning efforts at all levels of public health, such as needs assessments and public engagement plans.

# Introduction

## Rationale for the review

Communication lies at the 'heart of public health and plays a pivotal role in promoting core public health objectives...including disease prevention, health promotion and quality of life' [1]. The discipline of health communication has existed since the 1970s and is rich with theories, paradigms, debates and methodologies. Risk communication is one body of health communication theory, research and practice focused specifically on communicating the health risks caused by industrial technologies, environmental and natural hazards (including diseases) and human activities, amongst individuals, groups and institutions [2,3]. Effective risk communication is increasingly seen as crucial to the prevention and cooperative management of health risks; indeed, communication expertise has been recognised as at least equally essential to outbreak control as epidemiological training and laboratory analysis [4,5].

The overall aim of risk communication is 'to provide the public with meaningful, relevant, accurate and timely information in relation to ... health risks in order to influence choice' [6]. In the context of communicable diseases, particularly in the highly tense situations these diseases engender (for example, outbreak scenarios), effective risk communication is a complicated and challenging process. All risk communication operates in a realm of uncertainty: 'facts about the situation or event may be unclear and the science base underpinning potential responses imperfect' [6]. Communicable diseases in themselves are complex, dynamic and uncertain phenomena, with, for example, new viruses emerging; diseases previously considered eradicated re-emerging; and influenced by geography, diet, occupation, population growth, global travel, and countless other social and cultural behaviours and practices [7]. In addition, risk communication frequently operates in emotionally-charged environments as 'fear, anxiety, distrust, anger, outrage, helplessness, and frustration' [8,9] are common reactions to the health risks associated with communicable diseases. In such contexts, risk communication specialist Vincent T. Covello, and his colleagues highlight that the usual rules of communication often 'fall short or can make the situation worse' [10].

This review was commissioned by the European Centre for Disease Prevention and Control (ECDC), an organisation tasked from its establishment in 2005 with identifying, assessing and communicating information on current and emerging threats to public health from communicable diseases in the European Union (EU) Member States and EEA/EFTA countries [11]. ECDC 'serves 30 countries (with different communication capacities and resources) and various stakeholders in Europe with 25 official languages spoken. Communicating the scientific content generated by ECDC to meet the specific needs of the target audiences in a language and format that is adapted to and comprehensible by each audience is an ongoing challenge' [11] for the organisation. Thus, risk communication is further complicated by the complexity of the European region, with its significant geographic, cultural, economic and linguistic diversity.

Despite the many challenges to effective risk communication, Deborah C. Glik argues that 'as we collectively face potential disasters such as pandemic flu ... or other serious health threats, being able to communicate appropriately to the news media and to the public, although never assured, can be more closely approximated if basic principles of practice are followed' [3]. It is timely, therefore, to summarise and critique the key literature on risk communication for communicable diseases to better understand: (i) the principles that define effective and responsible communication; (ii) the particular body of knowledge, if indeed any, from which decision-makers should draw when designing risk communication strategies to address the prevention and control of communicable diseases in Europe; (iii) if there are general patterns, or specific examples, of 'good practice' that can be gleaned from the literature and applied to policy and practice in Europe; and (iv) what gaps and/or inconsistencies in the literature can be addressed by future research.

## Objectives of the review

This review aims to survey the current body of research and practice on risk communication related to communicable diseases, with the specific objectives of:

- clarifying the terminology and fundamental theories, concepts and principles used in the current risk communication landscape;
- identifying examples of effective risk communication for communicable diseases, applicable to the European context; and
- building on the best practice examples identified, offering suggestions for risk communication research, policies and strategies, adaptable to individual circumstances in Europe.

This review is intended to reach public health professionals, bodies and organisations active in the applied use of health communication and particularly risk communication in the prevention and control of communicable diseases in the European context. Other intended audiences for the review include health and risk communication practitioners and the public health research community.

## Structure of the review

The review begins with a concise summary of the methodology adopted for the literature search. Following this, the results of the review are presented, covering topics ranging from risk communication theories, methodologies, systems and guidance documents to insights, lessons learned and implications from the real-world application of risk communication principles over the past decade. Finally, the summary of findings offers a rationale for improving practice and conducting further research on risk communication for the prevention and control of communicable diseases.



# Methodology

## Search strategy

A number of databases were searched to locate published academic literature for the review: Embase; EPPI-Centre; MEDLINE; PsycINFO; SAGE Journals Online; Scopus; The Biomedical & Life Sciences Collection; The Campbell Library; The Cochrane Library; and Web of Science. In addition, three journals were extensively hand-searched for relevant articles: *Health Research Policy and Systems*, *Health, Risk & Society*, and the *Journal of Applied Communications Research*. The reference lists of documents retrieved from these sources were consulted to identify additional publications.

Papers, conference presentations, reports and technical documents, and other types of grey literature were identified through general internet searches, as well as targeted searches of the websites of the: Australian Institute for Health and Welfare; European Centre for Disease Prevention and Control (and the sites of the scientific and technical institutions that comprise its Competent Bodies); Health Canada; Health Protection Agency (UK); Infectious Disease Research Network; King's Fund; Centers for Disease Control and Prevention (US); and World Health Organization. Academic theses were located from the ProQuest Database of Dissertations & Theses and the Networked Digital Library of Theses and Dissertations. The reference lists of documents retrieved from all of these sources were consulted to identify additional key publications, thereby completing the 'data bank' for the review.

## Search terms

The search terms used to locate the literature for this review included, but were not restricted to:

- 'risk/crisis communication' AND 'communicable/infectious disease/outbreak';
- 'risk/crisis communication' AND 'communicable/infectious disease/outbreak' AND 'lesson/best practice/guidance';
- 'risk/crisis communication' AND 'communicable/infectious disease/outbreak' AND 'Europe/EU/EEA/EFTA'.

## Exclusion/inclusion criteria

The review concentrated on retrieving English language documents published between January 2000 and January 2011, with the exception of the websites of the ECDC's Competent Bodies located in Central and Eastern Europe. These sites were translated into English from their native languages (with the aid of an online translation service) in an effort to ensure representative data collection. The review concentrates on European examples of risk communication; however, there was no geographic restriction placed on the literature search.

# Results

## Introduction

Risk communication has flourished for decades in a number of applied disciplines (for example, environmental risk studies, disaster management, media studies); the theoretical and conceptual literature, in particular, is rich in these fields [3,12]. The body of research on risk communication in public health has also grown steadily since the 1990s, with the greatest number of studies for this review found on the topics of: risk communication theories and guidelines, risk perception, and lessons learned from the global outbreaks of sudden acute respiratory syndrome (SARS) in 2002/2003 and H1N1 influenza in 2009/2010. It is clear that the sub-field of risk communication on communicable diseases is still 'emerging' though as the body of research lacks both rigorous empirical evidence and evaluation research on 'event-specific risk communication efforts' [3], relying more instead on guidance documents, case study descriptions and theoretical insights from the broader literature on risk communication.

In total, 214 references were retrieved for this review and categorised into 24 thematic groups. This section presents and discusses results from the literature reviewed, highlighting key studies and synthesising and comparing results where possible. First, it brings readers up-to-date with the current literature on definitions and theories of risk communication; then, it highlights methodologies, tools and guidelines for risk communication research and practice; and, finally, the section presents implications, insights and key lessons learned from the application of risk communication principles to threats or outbreaks of communicable diseases.

## Defining risk communication

The literature reveals a number of definitions of risk communication [13]. At its most general, risk communication refers to an exchange of information about the 'health risks caused by environmental, industrial, or agricultural processes, policies, or products among individuals, groups and institutions' [3]. A number of the key features of effective risk communication are embedded in this definition, namely: risk communication is a *dynamic* and *interactive* process involving exchanges between *different groups* of key players and audiences. Covello & Sandman remark that the principle of involving the public in matters of risk, whether it is risk assessment, decision making, management or communication, marks one of the crucial distinctions of risk communication, in theory and practice, from a larger literature on crisis communication [8].

To continue with the distinction used in this review, risk communication is based on ongoing projections and calculations of the potential for future harm; crisis communication, by contrast, is a spontaneous and reactive process, often occurring in unexpected emergency situations [3,14-17]. Crisis communication messages are based on what is known and not known about a current state or condition (for example, its magnitude, immediacy, duration, control, cause, blame, consequences); risk messages, on the other hand, emerge long before a crisis event occurs, and aim to reduce the likelihood of a crisis event occurring in the long term [15,16]. According to Covello & Sandman, industries and governments historically ignored the public in matters of risk and crisis, their aim being to protect the public, rather than involve it [8]. As risk communication emerged as a body of theory and practice of its own, the public has played an increasingly important role in the management of risk issues and implementation and monitoring of risk management decisions. Today, there appears to be wide acceptance in the literature that effective and responsible risk communication encourages working relationships amongst all interested parties, including the public.

While this review assumes a distinction of risk communication from crisis communication, it is important to note that the terms are often used interchangeably in the literature. As such, both terms, crisis communication and risk communication, were included in the search strategy for this review. Also, while the authors have attempted to maintain the focus of this review on risk communication specifically (as defined above), many of the sources cited in the paper refer to risk communication in the context of emergency situations, thus adopting terminology such as 'crisis risk communication' or 'emergency risk communication' that blur the distinction between the two fields. Finally, the literature included integrative models, such as the US Centers for Disease Control and Prevention's influential *Crisis and Emergency Risk Communication (CERC)* – explored in the sections of this review on systems and tools and guidelines for risk communication – which propose to bring risk and crisis communication together.

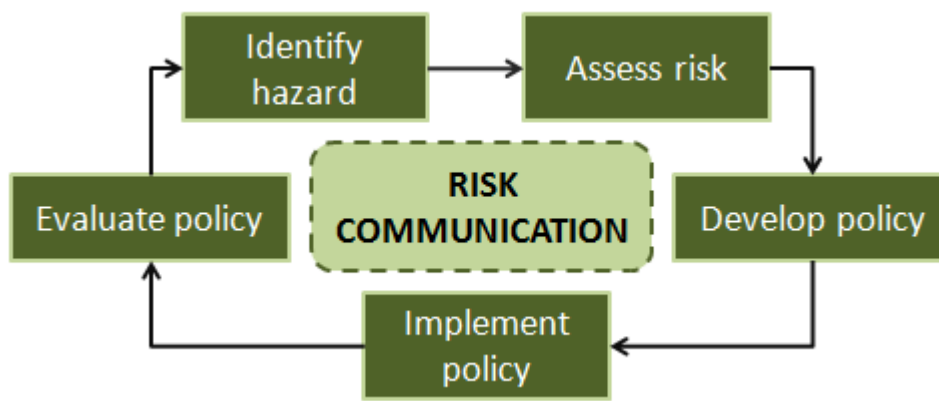
## Emergence and development of risk communication for communicable diseases

The literature indicates that the theories and practices of risk communication were extended markedly to the issue of communicable diseases around the mid-1990s, with initial studies building on health risk research by Covello, Paustenbach, Detlof von Winterfeldt and Slovic, amongst others [18-21]. Nicoll & Murray [22] and Reynolds & Seeger [23] suggest that risk communication was embraced in the field of public health as 'threats to health from

the likes of tuberculosis, HIV, influenza, anti-microbial resistance, chemical accidents and bio-terrorism' were recognised as not only ubiquitous but likely to be increasingly common 'with increased movements of people, animals and goods, climate change and industrialisation' [22]. In an era characterised by uncertainty, rapid change and globalisation, where national borders provide no barriers to the transmission of communicable diseases, and with new diseases emerging and the re-emergence of other diseases, the importance of models and guidelines for effective risk communication is clear [22-24]. In addition, Reynolds & Seeger note that the perceived threat and intentional nature of an anthrax attack in the United States in 2001, followed soon after by the emergence and global spread of SARS, 'placed significant pressure on the public health community to communicate effectively within context[s] of immediacy, threat and high uncertainty' [23]. This environment highlighted the weaknesses of the risk communication guidelines and models of the time for responding effectively to the threats to health that communicable diseases present.

Governments and health agencies responded with the rapid development of risk communication plans and guidelines, the vast majority locating risk communication as an essential component of the larger processes of risk analysis and management. Health Protection Scotland's guidance document for communicating with the public about health risks contains an illustrative model in this respect (6); the role that risk communication plays in the risk management process is evident (see Figure 1).

**Figure 1. The role of risk communication in the risk management cycle, adapted from (6,25)**



Today, it is widely recognised that effective risk communication is crucial for limiting morbidity and mortality from communicable diseases, in addition to minimising the potential damage that communicable diseases can wreak on national economies and public health infrastructure.

## Theories of risk communication, including perception of risk theories

Individuals are influenced by risk information in complex and unpredictable ways and the theoretical models on risk communication, particularly perception of risk theories, are prolific across many disciplines. This section offers an overview of the literature on four theoretical models of risk communication in particular, identified by Covello et al. in 2001: risk perception, mental noise, negative dominance and trust determination [14]. In addition, the section considers the more recent turn in the field to models emphasising the social and cultural factors that determine how risk information is processed and risk perceptions formed.

It is commonplace today to assert that 'Europeans live in a 'risk (perception) society'', writes Durodié, in 2006: 'What is significant is not the fact that we may be exposed to greater and more serious risks today than previously in history, but that we *believe* this to be the case' [26]. Risk perception, thus, is at least as significant as the concrete threats to which we are exposed. The risk perception model holds that there are a myriad of factors affecting how individuals perceive risk; for example, the voluntariness, equity, uncertainty, reversibility and origin (human versus natural) of the risk [9,27,28]. McInnes identifies the factor of 'agency' as particularly essential to shaping perceptions of risk, referring to whether there is a feeling that something can or cannot be done to control exposure to the risk [29,30]. In turn, these factors alter emotional, cognitive and behavioural responses to risk information and influence individual and collective levels of concern, worry, anger, anxiety, fear, hostility, and outrage [9,28,31-34]. Perceptions of risk, therefore, present significant challenges for risk communication efforts.

Few issues illustrate these challenges as well as the public controversy surrounding the combined measles, mumps and rubella vaccination (MMR) in the UK, which started in 1998 and continues today. While immunisation is 'the cornerstone of childhood disease prevention' and the MMR vaccine has proven to be a world-wide success [35], enduring public concerns about vaccination and falling uptake levels compromise health protection targets. The

initial response to this controversy from the public health community was to provide more information about the relative risks of the diseases as compared to the potential side-effects of the vaccination [36]. A decade later, however, it is increasingly accepted that the strategy of 'more risk communication' has not worked largely because it fails to capture the complex, nuanced and evolving social perceptions and interpretations of risk that influence both individual and public decisions to vaccinate. Petts & Niemeyer report the findings of a study of information strategies that parents use to make sense of health risk issues, particularly MMR, identifying the 'importance of social networks in reinforcing parental understandings and beliefs... [and revealing] a preference for personal and face-to-face engagement with health professionals' [35]. Other research maintains that risk communicators can overcome the challenges of perceptions of risk by implementing specific activities; for example, obtaining information through surveys, focus groups and/or interviews on public judgements and perceptions of risk for particular scenarios, and sustaining an interactive exchange of information with stakeholders about the identified areas of concern [14].

The second theoretical model of risk communication identified by Covello et al. in 2001 is the mental noise model. This theory seeks to understand how individuals process risk information in conditions of stress. The model holds 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' [27,37,38]. However, if they have a conceptual map or mental model to help them understand the risk, the information provided by risk communicators is more likely to be understood and accepted [39]. Glik et al. illustrate how this process works in theory with the following example: 'Although there may be resistance to information in crisis risk communication scenarios because of stress and high arousal states, information link[ing] ... a new illness that fits an infectious disease prototype will be more easily understood or assimilated if a person already has a mental model of how an infectious disease is transmitted' [40]. The mental noise model suggests that understanding a lay audience's cognitive beliefs about risk in high arousal states will help risk communicators to translate technical and scientific concepts into understandable messages [41]. The approach promotes the use of in-depth interviews and other means of information gathering, as used in audience research for social marketing, for example, to gather information about popular interpretations of risk and assist in tailoring risk communication messages [3,42]. In addition, it is important to ensure that risk communication materials are easily comprehensible and contain adequate repetition and visualisation in order to reach the intended audiences [14].

The negative dominance model is based on a central theorem of modern psychology: when people are upset they put greater value on losses and other negative information or outcomes than on gains or positive information and outcomes [3,14,43]. Practically, for risk communication, this means that negative messages should be counterbalanced by a larger number of positive or solution-oriented messages [44] or, more specifically, 'risk communications are most effective when they focus on what is being done rather than what is not being done' [14].

Finally, the need to establish trust with the public is fundamental to the effectiveness of risk communication messages and strategies [10,14,45,46]. However, trust determination theory maintains that when people are upset they commonly do not trust authority [3,47,48]. Trust, therefore, must be established well in advance of an actual crisis event. Research indicates that proactive community outreach is one of the most effective means for achieving this goal [49].

Since 2001, when Covello et al. identified the four theoretical models discussed thus far in this section, there has been a general shift in focus towards models emphasising the importance of social and cultural factors to public acceptance of risk messages and assimilation of risk information. These 'social constructionist' approaches build on many of the central tenets of the previously discussed frameworks, particularly the importance and role of public trust in the organisation or individual communicating risk to how the risk is actually perceived and acted upon. The social constructionist approaches maintain that risks and threats cannot be studied in isolation (that is, risk is not an objective factor but rather a socio-cultural process) [50,51]. In addition, different people and different communities may value similar risks differently or differ in their interpretation and weighing of specific information and types of knowledge related to the risk [52,53]. This is evident in studies indicating gender differences in risk perception, with research showing that men and women express different levels of concern about the same risks and, also, that men and women not only perceive the same risks differently, attributing different meanings to them, but actually perceive different risks altogether [54].

Other studies have been devoted to how minority populations perceive and respond to risk communication messages as, during recent outbreaks of communicable diseases, minority populations were found to be disproportionately affected [55-57]. During the 2003 SARS outbreak, for example, as the 'global media reported dramatic stories from Asia in print media, television and the Internet ... some persons became fearful or suspicious of all people who looked Asian, regardless of their nationality or actual risk factors for SARS, and expected them to be quarantined' [57]. In addition, some people who had recently travelled to areas where SARS was spreading isolated themselves despite not having symptoms nor being exposed to someone with SARS [57]. Given that fear of social marginalisation and stigma as a result of a disease outbreak can cause people to deny early clinical symptoms and may contribute to their failure to seek timely medical care [56], this example alone illustrates that subgroups of a population at risk of discrimination during a disease outbreak require special attention from public

health professionals [57,58]. The factors to keep in mind, in terms of acceptance of risk messages, include environmental, social and cultural characteristics; language preferences, such as the appropriateness of the language used, translation, and cultural sensitivity; and differing health beliefs, past experiences and attitudes toward health professionals and health interventions. Indeed, the quality of risk communication is based on its ability to meet the specific needs of all populations, especially those most vulnerable (at greatest risk) and most likely to experience communication gaps [55].

Overall, the literature on risk communication theories is rich and prolific but McComas's review of the development of the field over a ten-year period (1996–2006) underscores the challenges this diverse and multi-disciplinary pool of knowledge presents for risk communication practitioners: 'Perhaps due to this diversity [of knowledge and theories]', she writes, 'risk communication research presently is characterized by many, sometimes overlapping, variable analytic studies but few integrative theoretical frameworks' [59]. Thus, there is an imperative for future research to aim for more theoretical integration.

## Challenges of the European context for communicable disease risk communication

To compound the definitional and theoretical complexity of risk communication, and the countless factors influencing perceptions of risk, Europe's multi-cultural and multi-lingual environment presents its own set of challenges to effective risk communication on communicable diseases. Spika et al., at the WHO's Regional Office for Europe (WHO/EURO) in Copenhagen, Denmark, discuss the difficulties the region has encountered in meeting the WHO European regional targets for reducing the burden of communicable diseases using surveillance and immunisation programmes for measles-mumps-rubella (MMR) to illustrate. Their paper identifies a host of variables related to the cultural and economic diversity of the region as particularly salient challenges; for example, varying political will, capacities of health workforces and laboratory facilities [60]. The authors conclude with the suggestion that the solutions to achieving the targets for controlling MMR lie in the cooperation and collaboration of an international coordinating body with 'national immunization programs and nongovernment organizations. Such collaboration should improve the availability and the quality of information available to the public ... encourage full commitment of all governments, appropriate mobilization of resources, and realistic multiyear plans at the national level' [60].

In addressing challenges posed by the European context, Kittelsen, from the International Peace Research Institute in Oslo, Norway, urges European policymakers to accept a paradigm shift: 'In an interconnected world characterised by transnational flows of capital, labour, production and consumption, the threat of infectious disease in one locale carries ramifications throughout the global system ... [thus, to] effectively confront the challenge of infectious disease to the region, Europe needs to be understood less as a territorially bounded space, and more as a dynamic and fluid one' [61]. The emphasis of Kittelsen's paper on the global circulation of communicable diseases highlights, again, the significance of cross-sectoral and cross-national risk preparedness, surveillance, response and monitoring strategies, and cooperation and coordination throughout the region.

## Methodological approaches to risk communication research

Moving next to the academic literature on risk communication, a mix of quantitative and qualitative studies are found in the body of work; evaluative studies are noticeably missing. There is clear value in both quantitative and qualitative approaches to the study of risk communication with each tradition bringing unique perspectives to bear and realities to light.

Woolhouse summarises the role and challenges of quantitative approaches in a recent (2011) review paper for *Philosophical Transactions of the Royal Society: Biological Sciences*, also shedding light on areas for future research [62]. The strength of quantitative approaches, for Woolhouse, is in making predictions about the likelihood of an infectious disease outbreak, how the disease will spread, and how to control it. Towards this end, several well-established methodologies are available, including risk factor analysis, risk modelling and dynamic modelling. Woolhouse argues, however, that there is still need for quantitative analyses that account for the nonlinear dynamics of infectious diseases and the development of more holistic research frameworks that can capture the underlying drivers of disease risks, such as climate change and human impact on the physical environment [62]. Finally, there is considerable room for improvement in how quantitative research is communicated to end users, particularly policy makers [62].

Qualitative studies on risk communication for communicable diseases have been employed largely to tap into the complex factors involved in people's ambivalences, perceptions, and responses to risk [63-66]. In addition, a number of qualitative techniques of data collection, such as focus groups and interviews, have been used to develop and test risk communication messages, including the 'understandability, believability and credibility of the messages, as well as level of interest in the subject, perceived importance of the information, likelihood of action after being exposed to the information and unanticipated consequences of the information' [66]. Such avenues of

research continue to merit further study as better understandings of the complicated roles of psychological, social and cultural influences on risk perception are fundamental to realistic planning for risk communication [59,67,68]. Holmes (2008), in an article in *Health, Risk & Society* on the importance of research on emerging infectious disease, identifies a number of areas, still little explored, in which qualitative studies could be extended [68]. She suggests, for example, that there is scope for qualitative studies on the ideological, political and ethical implications of risk communication, such as the tension between the increasing focus on individual choice and responsibility in many health systems today, with the goal of public 'compliance' that is often necessary during an outbreak, or threat of an outbreak, of a communicable disease [68-70].

Finally, before exploring systems and tools for risk communication, it is necessary to consider explanations for the lack of evidence-based evaluations of risk communication on communicable diseases in the literature. Thomas et al. explain that evaluating risk communication is 'fraught with challenges,' such as the need to consider all stakeholders' perspectives; account for various channels of influence (mass media, various levels of government, law enforcement, etc.); devise appropriate questions and timing (what and when to measure?); and all within the dynamic and contextual nature of high-concern, even emergency, situations [71]. Despite the challenges, Glik argues strongly that evaluation research is fundamental for understanding the effectiveness of risk communication, particularly as it unfolds in crisis communication events [3]. Her 2007 review provides a number of concrete suggestions for future evaluation research; for example, process tracking to determine where messages are placed during a crisis event and opinion surveys to assess the degree to which specific communities are exposed to communication messages and how these messages are assimilated.

## Systems and tools for risk communication

This review revealed a small but distinct body of work either describing or recommending specific systems, models or tools to facilitate risk communication on communicable diseases. Some of this work responds to the concerns identified in the preceding section on the need for coordinated surveillance structures and systems to better monitor and report on risks and outbreaks of communicable diseases across Europe. For example, papers on SmiNet-2, Sweden's regional/national system for communicable disease surveillance [72]; SurvNet@RKI, Germany's electronic reporting system for surveillance of infectious diseases [73]; and Germany's recent efforts to improve its pandemic preparedness plans [74] showcase national investments in electronic systems for the enhanced quality of communicable disease surveillance, simplified reporting, improved completeness, and increased timeliness. Castkova, too, from the National Institute of Public Health in the Czech Republic, lists efforts made in her country to ensure effective monitoring and analysis of the epidemiological situations of communicable diseases at both the national and international levels. This includes implementation and ongoing assessment of surveillance programmes; participating in the European infectious diseases notification networks; development of national legislation supporting guidelines for responses to communicable diseases; reporting cases of infectious diseases at a country-wide level into centralised databases; and regular analyses of epidemiological data related to communicable diseases; amongst other country-specific activities [75]. Thus, it appears there are current and relevant examples of good practice in the development of planning and preparedness tools to assist with monitoring, responding to and ultimately communicating the risks of communicable diseases in the European region.

There are also a number of studies in the literature on the Crisis Emergency and Risk Communication (CERC) model developed by the US Centers for Disease Control and Prevention (CDC) in 2002 [see [23,76] in particular]. Various descriptions in the literature, as a model, tool, training module and framework, CERC merges many of the traditional principles of risk communication with work in crisis and disaster communication. For risk communication practitioners, CERC offers course materials, including books and videos; online training; on-site training; and accredited certification (RiskSmart). The CERC tool also provides health communicators with steps for communication over five phases of an emergency situation caused by an outbreak (or threat of an outbreak) of a communicable disease: (i) pre-crisis phase (risk messages, warnings, preparations); (ii) initial event phase (uncertainty reduction, self-efficacy, reassurance); (iii) maintenance phase (ongoing uncertainty reduction, self-efficacy, reassurance); (iv) resolution phase (updates regarding resolution, discussions about cause and new risks/new understandings of risk); and (v) evaluation phase (discussions of adequacy of response, consensus about lessons and new understandings of risks) [23].

The CERC toolkit has been tested over the past ten years since its development, particularly during the global influenza pandemic of 2009 [77]. Overall, research indicates that CERC is a valuable and 'internationally recognized communication model' [78]. Recent papers, though, propose either to update or extend the model in order to reach new audiences and communities. Crouse Quinn, for example, in an article published in the aftermath of Hurricane Katrina in the United States (2008), remarks that the hurricane made 'evident some critical challenges in ... communication between government and minority communities' during crisis situations [77]. Crouse Quinn's paper proposes to incorporate some of the tools of community development and participatory action research into CERC to build the capacities and resilience of minority communities to respond to disasters and pandemics, and to help develop trust between government agencies and minority communities in the periods between emergency situations [77]. Hewitt et al., also in 2008, suggest that a valuable opportunity exists today to introduce CERC to a

new population: general healthcare managers and administrators [78]. The authors write that 'the CERC toolkit and resources provide an easy, turn-key solution and a validated template for educators who are not directly involved in public health education but desire to share this content. In [their study], graduate students enrolled in a Master of Health Administration program used a Play2Train scenario, located in [a] virtual learning environment ... to incorporate concepts from the CERC model ... learn[ing] collaboration and leadership competencies' [78]. The study suggests that extending the CERC model to all health professionals could enhance the overall effectiveness of risk and crisis preparedness planning.

The next section moves from specific tools and models to generic guidance, or sets of principles, for effective risk communication.

## Guidelines on the 'rules' and essential elements of effective risk communication

There are a vast number of guidance documents in the literature, outlining principles, rules or elements of effective risk communication. Most of these documents have been developed by government agencies and international organisations. Four review papers assist in bringing together the key guidance documents which have informed much of risk communication policy and application over the past two decades: Jardine et al.'s 2003 publication, *Risk Management Frameworks for Human Health and Environmental Risks* [79]; Glik's 2007 review, *Risk Communication for Public Health Emergencies* [3]; the Health Protection Network of Scotland's guidance document, *Communicating with the public about health risks*, published in 2008 [6]; and, finally, Abraham's recent (2011) review, *Lessons from the pandemic: The need for new tools for risk and outbreak communication* [80].

To begin, Jardine and her colleagues examined more than 100 risk documents from over 80 agencies, organisations and advisory councils between 2000 and 2002, ultimately selecting 12 documents published between 1983 and 2002 for extensive review: [81-92]. Six of these frameworks were developed by Canadian agencies; four come from the United States; and one document each stem from Australia and the UK. The documents were selected according to their representativeness of generalisable, comprehensive and well-defined approaches to health risk which, at the time, drew heavily from the field of environmental health risk management (seven of the 12 frameworks). The other frameworks represent occupational health risk assessment and management and general understandings, management and determination of health risks.

Based on extensive review of the 12 sets of guidelines, seven key elements were identified as essential for a comprehensive risk framework for human health: (i) problem formulation; (ii) stakeholder involvement; (iii) communication; (iv) quantitative risk assessment components; (v) iteration and evaluation; (vi) informed decision making; and, lastly, (vii) flexibility. Building on this seven-step approach to risk management, Jardine et al. also created a checklist for ensuring effective and responsible risk management decisions, including principles such as: committing to honesty and open communication between all parties; acknowledging the multiple dimensions of risk; and employing continuous evaluation throughout the process (amongst others). Finally, the authors synthesised their guidance frameworks into a set of 10 decision-making principles for risk management, including risk communication:

- Do more good than harm (beneficence, nonmalficence).
- Ensure an equitable distribution of risk (equity).
- Fair process of decision making (fairness, natural justice).
- Seek optimal use of limited risk management resources (utility).
- Promise no more risk management than can be delivered (honesty).
- Impose no more risk than you would tolerate yourself (the Golden Rule).
- Be cautious in the face of uncertainty ('better safe than sorry').
- Foster informed risk decision making for all stakeholders (autonomy).
- Risk management processes must be flexible and evolutionary to be open to new knowledge and understanding (evolution, evaluation, iterative process).
- The complete elimination of risk is not possible (life is not risk free).

When Glik's review was published in 2007, four years after Jardine et al. had synthesised their set of 12 guidance frameworks, there were many new documents available, now focused specifically on risk communication (rather than identifying risk communication as a component of the larger process of risk management) and representing risk communication specific to the field of public health. Indeed, as previously mentioned in this review, governments around the world had been catapulted into action following the global outbreak of SARS in 2003, revising, updating and creating new guidance documents for risk communication specific to the prevention and control of communicable diseases (23).

Glik's goal for her review was originally broader than examining the available guidance frameworks; she set out to summarise theories and examples of 'research that inform current practice in crisis risk communication for public health' [3]. However, she discovered that most of the examples 'f[e]ll short of systemic evaluations of how

effective risk communication ... [was] during actual crisis communication events' and thus opted for an alternative approach for her review; namely, assessing 'the current content of readily available ... crisis risk communication guidelines and curricula.' At the time of writing, Glik located five sets of such guidance documents, mostly focused on risk communication in crisis or emergency situations:

- The CDC's *Crisis and emergency risk communication (CERC)* by Reynolds et al., discussed in the previous section on systems and tools for risk communication [93].
- The *Primer on health risk communication principles and practices*, by Lum & Tinker of the U.S. Agency for Toxic Substances and Disease Registry [94].
- The U.S. Department of Health and Human Services' document, *Communication in crisis: risk communication guidelines for public officials* [95].
- *Risk communication with the media during a public health crisis*, developed by Covello for the Heartland Center for Public Health Preparedness at Saint Louis University [96].
- The *Crisis and emergency risk communications toolkit*, published by the California Department of Health Services [97].

Glik's summary of the five sets of guidelines is concise: they are of varying depth and quality; all stress 'organizational development, message development, audience research, audience relations, message delivery, and media relations' [3]. The following best practices for risk communication practitioners were gleaned from Glik's review of guidelines:

- The importance of message consistency; specifically, multiple, consistent messages are typically more effective than single messages or inconsistent messages.
- The accuracy of messages is fundamental, as errors in past warnings have resulted in people failing to respond to subsequent warnings.
- Messages containing instructions on appropriate or recommended actions must be specific; that is, they need to provide the intended audiences with precise details on 'what, when, how, and for how long'.
- Risk messages and approaches should be tailored for the diverse audiences they are intended to reach, taking into account differences in and the influences of social, cultural and demographic backgrounds.
- Risk communication messages should be (pre-)tested extensively before crisis situations, particularly amongst at-risk and hard-to-reach communities.

The next document reviewed in this section is a handbook published in 2008, *Communicating with the public about health risks* [6], following creation of a working group within Scotland's Health Protection Network (HPN) tasked with searching the international literature to identify best practices in risk communication. The working group identified and synthesised seven sets of guidelines into a reference guide of its own for risk communication practitioners. The primary documents (sets of guidelines) synthesised include:

- the CDC's *Crisis & emergency risk communication: by leaders for leaders* [98];
- a report of the WHO Expert Consultation on Outbreak Communications, *Singapore outbreak communication: best practices for communicating with the public during an outbreak* [99];
- *Communicating about risks to public health: pointers to good practice*, written by Bennett at London's Department of Health [100];
- the US Department of Health and Human Services' document, *Communication in crisis: risk communication guidelines for public officials* [95];
- the Washington, DC-based Federal Communicators Network's, *Communicators guide for federal, state, regional, and local communicators* [101];
- *Guidelines on science and health communication*, a collaboration of the Social Issues Research Centre, Royal Society and Royal Institution of Great Britain [102]; and
- the British Broadcasting Corporation's *Guidance note on editorial policy: reporting risk* [103].

The documents reviewed for the HPN handbook reflect a more European focus than the previous sets of guidelines synthesised by Jardine et al. and Glik. The HPN book differs from the other two reviews in its presentation, as well. Rather than being an academic journal article, its intended audience is the UK's National Health Service public health and communications staff, partner agencies, the health media and other public health agencies. Consequently, the findings were synthesised into a concise handbook of definitions, principles, tips and exercises for practitioners planning and delivering risk communication.

It is noteworthy that of the 24 sets of guidelines listed in this section thus far, only two of the same documents were identified more than once by the reviewers, both US publications: the CDC's CERC module [98] and the US Department of Health and Human Services' *Risk communication guidelines for public officials* [95] (both found in the Glik and HPN reviews). A number of the same best practices or elements of effective risk communication are identified in all three of the review papers, however. These include:

- Good risk communication engages with and responds to the communities it intends to reach: stakeholder involvement, including pre-testing of risk messages and tailoring for specific audiences, is essential for the efficacy and impact of risk communication. In addition, to communicate effectively about risks to the health



of the public, working relationships amongst all parties involved must be strengthened and mutual trust promoted.

- Risk communication is an integral component of a larger framework for risk management.
- Effective risk communication ensures clear objectives, consistent messages, and transparent and credible decision-making.
- Communicating risk effectively requires not only the provision of information, but also explanations of the complexities and uncertainties associated with the nature, magnitude, significance and control of a risk.

The influenza pandemic of 2009 provided an opportunity for governments and health agencies around the world to test the existing guidance documents for risk and outbreak communication (as with the CERC toolkit discussed in the preceding section). According to Abraham, the scope of the pandemic demonstrated the usefulness of existing tools and concepts in the guidance documents as well as exposing challenges, gaps and limitations in their understanding and application [80]. Abraham's review article is the final one discussed in this section. He focused his review on the WHO's 2005 Outbreak Communications Guidelines [4] and, once again, the CDC's CERC guidelines and training module [93]. Both of these documents, according to Abraham, concentrate almost exclusively on emergencies and outbreaks. An influenza pandemic, however, is more than an outbreak, and the 2009 pandemic brought to light a host of questions not well covered in the guidance documents Abraham surveyed, such as: the necessity for vaccination and vaccine safety; the general quality of public health responses to influenza; and long-term health communication and health promotion strategies focused on behaviour change (for example, cough and sneeze etiquette). This was also the first pandemic of the internet age, and Abraham makes a strong case for the need to update existing guidance documents with strategies for effective web-based communication and use of social networking tools to reach audiences during outbreaks of communicable diseases and address longer-term health threats.

Finally, Abraham demonstrates that there is still continued room for improvement in risk communication policy, guidance and research on how to build and maintain trust with the public before, during and after outbreaks of communicable diseases. While the guidance literature describes various components of building trust (for example, communicating objectively, consistently and transparently), and emphasises the significance of trustful relationships to the overall effectiveness of risk communication efforts, the 2009 pandemic made it clear that establishing trust requires far more than applying guidelines during a crisis situation. Rather, communicating agencies must commit to policies of openness and transparency in their general operations. Further research is also necessary to better understand the complex factors that result in low public trust in communicating agencies from situation to situation.

## Applying risk communication: implications, lessons learned, insights and gaps

One of the fundamental aims of this review is to elicit information for developing effective, responsible, evidence-based strategies and approaches to risk communication for communicable diseases. This final section of results moves towards this end by summarising lessons learned from examples of applications of risk communication guidance and principles. In the process, implications, insights and gaps in risk communication research, policy and practice on communicable diseases are highlighted.

More than 60 documents were surveyed for this section of the review, including examples from studies of public health responses to the threat of anthrax and other emergencies linked to bioterrorism; risk communication related to HIV/AIDS, tuberculosis, the West Nile virus, SARS and H1N1 influenza; vaccine risk communication, particularly in relation to the controversies surrounding the measles-mumps-rubella vaccine in the UK; and general pandemic preparedness and risk communication. The studies represent research undertaken mainly in Europe, southeast Asia and North America. The following list of lessons learned synthesises implications and insights garnered from this body of research:

- Studies by Crouse Quinn [77], Reynolds [104], Braverman et al. [105], and Blumenshine et al. [106] demonstrate that risk communication for communicable diseases often fails to reach its intended communities, including those people most at risk of the disease. In order to better tailor risk communication messages to reach and resonate with all intended audiences, the studies suggest there is a need for additional qualitative research on the public's diverse knowledge, understandings and perceptions of risk; preferred sources of risk information; and general health beliefs, particularly with minority and hard-to-reach communities [107-110]. In addition, it is essential that the findings of these studies are communicated to policy-makers and public health agencies to inform risk communication planning, guidance and training.
- Building trust with the public is essential for risk communication to be effective but difficult to achieve in practice. As such, future risk communication research and practice must continue to place emphasis on (i) uncovering how to use communications to build public trust; (ii) measuring baseline levels of awareness and perceptions of potential risks, and willingness to comply to risk communication messages [80,108,111-

113]; and integrating models of long-term behavioural change into risk communication tools, models and guidelines [80,112].

- Despite the advice in the guidance documents, and the availability of various planning tools for pre-crisis event risk communication and readiness efforts, studies on how countries actually respond to emergency situations involving communicable diseases reveal that many still need to concentrate on advanced planning at all levels of public health [113-116]; for example, conducting needs assessments, contingency planning and other preparedness and public education and engagement plans. For Fisher et al. (2011), for example, the 'major lesson on reflection of the 2009 H1N1 outbreak is that we were only saved because the infection turned out to be relatively mild' [115]. The pandemic demonstrated that despite years of apparent preparations, the public health, government and research communities were still not ready to respond to the challenge of dealing with a discrepancy between what was expected and what actually emerged (in this example, planning was for a highly virulent avian influenza virus but, in fact, what emerged was a less virulent influenza). A relevant suggestion in the literature for improving communication regarding communicable diseases is to test risk communication principles under simulated conditions of time pressures and stress [66,68,117]. In this respect, the ECDC has a significant role to play as a leading agency in the region, having both: (i) developed a system for crisis management (the Public Health Event or PHE plan) which was extensively tested during the 2009 influenza outbreak, and proved to be flexible and responsive enough to allow the organisation to rapidly identify and correct problems to its response efforts; and (ii) demonstrated 'an impressive capacity to learn from real and simulated (exercise-based) experience of public health emergencies', according to a recent evaluation of the organisation's response to the 2009-2010 influenza pandemic [118].
- A similar lesson gained from reflection on the 2009/2010 influenza pandemic is that the research community needs to be better prepared to conduct studies during and immediately after the outbreak of a communicable disease [115]. Many of the areas of substantial controversy during the influenza pandemic experience were linked to gaps in the evidence base, such as 'the optimal approach to respiratory protection of healthcare workers' [119]. Thus while research is essential in non-outbreak phases (particularly on risk perceptions) it is also important for the public health and clinical research community to initiate research immediately at the onset of an outbreak period to identify the weaknesses of 'health systems at ... international, national, regional or even individual facility level[s]' [115].
- A number of challenges have surfaced in recent years in relation to vaccination for pandemic influenza, including vaccine availability, long-term safety, and efficacy [120]; the varying capacities of the health systems in the European region to administer vaccination [121]; and public perceptions of and willingness to be vaccinated [122,123]. Research also indicates that 'screening and quarantining entering travelers at international borders [has] not substantially delay[ed] virus introduction in past pandemics, except in some island countries, and will likely be even less effective in the modern era' [124]. A potential solution to some of these challenges, identified in the literature, is to focus on risk communication interventions at the national and even community levels [124]. At minimum, there is evidence that risk communicators should provide information in close collaboration with community-level health services, care providers and media to build and maintain public trust [123]. This is further supported by studies on how the public prefers to receive risk messages. Henrich & Holmes, for example, conducted recent focus group research in Canada, concluding that the public prefers to receive information on health risks 'from family doctors, the Internet, and schools' [125].
- At a conference in 2010, Vincent T. Covello presented a summary evaluation of the US CDC's actual communications regarding H1N1 in 2009 as compared to key concepts from the risk communication literature [126]. His evaluation shows that an enduring challenge of risk communication is persuading the public and political actors to think probabilistically. Covello quotes Peter Sandman in his presentation: 'Public health officials need to insist on their uncertainty. They need to make uncertainty the message, not the preamble to the message'. He argues that research continues to demonstrate that the public trusts most those whom are willing to acknowledge the importance of uncertainty in their communication messages, using the example of messages about estimates of H1N1 vaccine available in the USA in 2010: this information should have been better bracketed with statements about uncertainty as public concerns about shortages of vaccine caused widespread distress.
- While HIV/AIDS has started to be recognised as a chronic illness in Western Europe, rising rates of infection in central and eastern Europe ensure the virus continues to constitute a public health concern for the entire region. Similarly, tuberculosis rates are high and rising throughout eastern Europe and central Asia, and the potential for an outbreak in surrounding regions is not only real but heightened by travel and migration patterns [127]. Two important lessons learned for risk communication practitioners from the rising rates of HIV/AIDS and tuberculosis in Europe are that (i) communicable diseases can have destabilising effects on the functioning of societies; (ii) and the spread of such diseases 'in a world characterised by transnational systems of circulation ... is as much a concern for other regions of the world, such as the EU, as it is for those regions where the diseases are most concentrated' [61]. The imperative, therefore, to ensure

effective risk communication, is to put emphasis on coordinated regional and international systems of monitoring and surveillance, in addition to addressing the 'economic, political and structural conditions that enable infectious diseases to flourish' [128].

- Menon's 2008 case study of Singapore's efforts to manage risk communication related to a potential avian flu (H5N1) pandemic highlights some lessons for other countries as well. Singapore was widely praised for its handling of the SARS epidemic in 2003; the country received international accolades for its decisive leadership at an early stage; the transparency and honesty of its communication messages; and earning the trust and confidence of Singaporeans with both symbolic and substantive measures to reassure the populace [129, 130]. Building on these successes, the Ministry of Health in Singapore began developing risk communication strategies and plans for a potential avian influenza pandemic in early 2005. However, Menon points out that the government's campaign efforts confronted numerous unanticipated challenges: 'From the start, it was clear that repeated references to the SARS experience would not do. It would generate complacency and a false sense of security in the populace that a repeat of similar measures would suffice to see Singapore through a pandemic' [130]. Other challenges included public indifference and fatigue to risk messages. The lessons to be gained from these challenges, according to Menon, are that careful planning and preparations are still the only sensible option but, over the longer term, further research is needed into the reciprocal influences of epidemiology and behavioural choice 'to better understand how people gather information, how it is conveyed to them, how they formulate their own perceptions of risks and make decisions to help themselves and their families in infected situations' [130].

## Summary of findings

This review has brought together the current body of literature on risk communication (focused on communicable diseases) in a concise reference document which can be used to inform the development of evidence-based risk communication strategies and approaches.

The review demonstrates that there is an impressive body of literature on risk communication relevant to the prevention and control of communicable diseases. This literature is complicated, however, by blurred definitions and overlap between risk communication and crisis communication. It is also widely dispersed across academic disciplines, lacking rigorous empirical evidence to demonstrate effectiveness, challenged by the complex and unpredictable ways that individuals perceive risk and the environmental, social, cultural and linguistic factors through which risk communication is viewed.

At the European level, there is a need to bring the work on risk communication for communicable diseases together on many levels:

- Theoretical models of risk communication must be integrated across disciplines.
- The bridge between academic research and risk communication in practice needs to be strengthened (that is, findings of research need to be better communicated to end users and built into risk communication planning, guidance documents, training modules).
- Risk communicators should be collaborating more closely with community-level health providers and media.

In addition, there is consensus in much of the literature reviewed on the need for coordinated leadership at the European level to ensure structured and systematic approaches to risk communication planning, preparedness and response.

We have a clearer picture today than a decade ago about the requirements, parameters and challenges of communicating risks of communicable diseases but there is still a need for a more general shift from emergency response to communicable diseases towards effective risk communication long before any crisis event emerges.

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