

## Chapter 35

# Stakeholder Involvement in Outbreak Management: To Fear or Not to Fear?

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## ABSTRACT

*Infectious diseases remain a threat to public health, requiring the coordinated action of many stakeholders. Little has been written about stakeholder participation and approaches to sharing information, in dynamic contexts and under time pressure as is the case for infectious disease outbreaks. Communicable-disease specialists fear that delays in implementing control measures may occur if stakeholders are not included in the outbreak-management process. Two case studies described in this article show how the needs of stakeholders may vary with time and that early sharing of information takes priority over shared decision-making. The stakeholders itemized their needs and potential contributions in order to arrive at the collective interest of outbreak management. For this, the results suggest the potential for improvement through development of “network governance” including the effective sharing of information in large networks with varying needs. Outbreaks in which conflicting perceptions may occur among the stakeholders require particular attention.*

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## INTRODUCTION

Past and recent (inter)national disease outbreaks such as the SARS outbreak 2003 (Timen et al., 2006; Wong et al., 2017), H1N1 pandemic 2009 (Fineberg, 2014), the Q-fever outbreak in the Netherlands 2007-2011 (Dijk, 2010; Dijkstra et al., 2012; Kampschreur et al., 2014; Van Asseldonk, Prins, & Bergevoet, 2013), Ebola epidemic in West Africa in 2014/2015 (Gostin & Friedman, 2015; Swaan et al., 2016) and the outbreak of Zika Virus (Vest, 2016) underline the importance of adequate preparedness, such as developing guidelines, aligning activities in communication networks and conducting simulation exercises. However well prepared we are, new diseases and new outbreaks will occur. Effective outbreak management remains an important public health practice, including identifying the source, implementing control measures to prevent further transmission, and risk communication.

The management of outbreaks, small or large, requires timely and adequate risk assessment, and risk management involving a wide range of stakeholders. These may include, for example, healthcare providers, public health services, representatives of or intermediaries for a wide variety of possible risk groups (e.g. patient organizations, hunters, youth workers, farmers or plumbers), and governmental agencies including Ministries of Health and Agriculture. Other stakeholders may include those related to the economic impact of diseases and control measures, such as those individuals and businesses concerned with the production, trade and export of (animal) products. The present dominant culture of transparency and increased participation has led to the (appeal for) increasing involvement of the public and other stakeholders in risk management and decision-making processes for risk mitigation (Hage, Leroy, & Petersen, 2010; IRGC, 2017, 2018; Metze & Turnhout, 2014; Runhaar, Driessen, van Bree, & van der Sluijs, 2010). The authors propose that outbreak management might benefit from deliberate stakeholder identification and inclusion, without any retarding effect, which can add essential insights and perspectives to the control of infectious diseases (Huizer, Kraaij-Dirkzwager, Timen, Schuitmaker, & van Steenberg, 2015; Roodenrijs, Kraaij-Dirkzwager, van den Kerkhof, & Runhaar, 2014).

From the point of view of outbreak managers, the relevance of the stakeholders varies. Contributions may include: the provision of information about the current situation and risk perceptions, the sharing of expertise in areas such as “best practices,” scientific insights and diagnostics, and the implementation of (control) measures. The stakeholder, individual or collective, may further be a source or susceptible host of the disease and therefore need to take preventive control measures to reduce the risk of transmission. Appropriate control measures are both topic- and context-specific. Information related to the specific context of an outbreak is essential and may include the cultural beliefs of stakeholders or perceived barriers to the implementation of control measures. However, while recognizing the potential benefits of stakeholder involvement, communicable-disease control specialists may also be somewhat apprehensive of stakeholder participation. The reason for this has its origin in the varying perspectives (‘frames’) and perceived conflicting interests stakeholders might bring to the process, regarding, for instance, possible delays in implementing, and also the effects of control measures.

The “frame” or “discourse” of each stakeholder can be seen as a cognitive framework, comprising values, concerns and interests that can provide a way to make sense of a complex reality, and also governs the subjective meaning assigned to societal events (Clahsen et al., 2018; Grin & van de Graaf, 1996; Rein & Schön, 1996; Scholten & Van Nispen, 2008). In general, frames can be seen as consisting of two orders of arguments. First-order frames deal with argumentation about the situation: the technical aspects of the problem at hand, and the effectiveness of the proposed intervention. The second-order frame focuses on the more general perceptions and values that underlie the argumentation in the first;

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