Building Trust, Managing Risk and rumours: The case of epidemics

Heidi J Larson, PhD
London School of Hygiene & Tropical Medicine
22 March 2017
ANTWERP
“The days when health officials could issue advice, based on the very best medical and scientific data, and expect populations to comply, may be fading.”

Margaret Chan, WHO Director-General
Report to the 126th Executive Board, 2010
The Decline of Deference: The Political Context of Risk Communication

Frank N. Laird

The Decline of Deference

Fig. 2. Percentage of people expressing “a great deal of confidence” in the leadership of various institutions.
Trust is in crisis globally, with 19 of the 28 countries we poll annually now distrusting states. Trust in the four institutions of business, government, media and NGOs have all declined this year with media witnessing the biggest falls.

**TRUST INDEX: A WORLD OF DISTRUST**

*Average trust in institutions, 2016 VS 2017*

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**TRUSTERS**

60-100

**NEUTRALS**

50-59

**DISTRUSTERS**

1-49

Source: 2017 Edelman Trust Barometer. The Trust Index is an average of a country’s trust in the institutions of government, business, media and NGOs. General Population, 28-country global total.

Trust declines in 21 of 28 countries—the broadest declines since beginning General Population tracking in 2012. 2 in 3 countries are now distrusters.
On trust
“actions and intentions”

Trust can be defined, first of all, as a state of favourable expectation regarding other people’s actions and intentions. As such it is seen as the basis for individual risk-taking behaviour (Coleman 1990), co-operation (Gambetta 1988), reduced social complexity (Luhmann 1979), order (Misztal 1996), social capital (Putnam 2000). It is an act that enhances the possibilities of transactions and contracts, and that increases the likelihood of

Guido Möllering
The Nature of Trust
Fear and emotion
The neglected dimension of health
Outbreak of emotion?

Fig. 1. Map of Belgium showing the location of the schools where the outbreaks took place (with date of outbreak and number of children involved), and the site of the bottling plants—Antwerp (which served Bornem) and Dunkerque, France (which served the other locations).
YOU'RE ALL GOING TO DIE

Yes, you should be afraid of avian flu

by David S. Bernstein | p. 6
Major motives in non-acceptance of A/H1N1 flu vaccination: the weight of rational assessment.

Gertner institute for Epidemiology and Health Policy Research, Tel-Hashomer, Israel. baruchv@gertner.health.gov.il

Abstract
Recent efforts of health authorities to promote vaccination against influenza A/H1N1 were met with low compliance rates in most industrialized countries. Here we analyzed the attitudes of the Israeli public towards A/H1N1 vaccination based on a telephone survey conducted several months after the peak of the outbreak. The findings attest to the low uptake of the A/H1N1 vaccine (17%) in Israel, and identify the socio-demographic characteristics associated with non-compliance.

Determinants of Refusal of A/H1N1 Pandemic Vaccination

Israel

Doctors refuse to take H1N1 vaccine

Published: Saturday, Feb 13, 2010, 0:28 IST
By Nozia Sayyed | Place: Mumbai | Agency: DNA

About 80% of the state medical fraternity is unwilling to be vaccinated against swine flu. Of the total 34,000 doctors, nurses and other paramedical staff in the state working to treat swine flu patients, only 5,300 have showed willingness to take the swine flu vaccination.
Fertile ground and amplifiers for rumours

A PSYCHOLOGY OF RUMOR

By ROBERT H. KNAPP

In the interim between world wars, rumor received scant attention from the social scientist. The neglect was understandable. Rumor thrives only in periods of social duress. In the calm of peacetime, there were other, more interesting topics to be investigated. But with the appearance of the second World War, attention was again forcibly drawn to this subject; increasingly it became apparent that wartime rumors not only impair public morale and confidence, but are in many instances the deliberate weapon of enemy propaganda.
Rumours have public health impacts

A warning from history: how the polio virus escaped the GPEI

Report of the Independent Monitoring Board of the Global Polio Eradication Initiative
November 2012
Vaccine rumors travel globally, can evolve quickly (or slowly)

Ten years later: 2013

How the CIA’s Fake Vaccination Campaign Endangers Us All

The U.S. was wrong to use health workers to target Osama bin Laden

Kano shuns Nigeria polio campaign

2003

Some 15 million children in West Africa are at risk of contracting polio.

The WHO is carrying out anti-polio vaccinations in the six worst affected states in Nigeria - except Kano.

Datti Ahmed, the President of the Kano-based Sharia (Islamic Law) Supreme council, has told the BBC that the vaccine in Kano is part of a plot to sterilize Muslims through a polio vaccine. He has asked his followers to stay away from the exercise.

The BBC has received these allegations via text messages. We have not been able to independently verify the allegations.

Muslim leaders in the historic city say the vaccine has been laced with anti-fertility drugs.
Sterilizing Vaccines or the Politics of the Womb: Retrospective Study of a Rumor in Cameroon

In 1990 a rumor that public health workers were administering a vaccine to sterilize girls and women spread throughout Cameroon. Schoolgirls leapt from windows to escape the vaccination teams, and the vaccination campaign (part of the Year of Universal Child Immunization) was aborted.
Kenya Catholic Church tetanus vaccine fears 'unfounded'

13 October 2014 Last updated at 19:58 BST

Kenya's government has dismissed allegations made by the country's Catholic Church that a tetanus vaccine can cause sterility in women.

"It's a safe certified vaccine," Hezron Mwangi, spokesperson for the Health Ministry, told the BBC.

Catholic priests have been telling women not to have sex during the campaign that begins on Monday.

Dennis Okari reports from Nairobi.

Kenya Catholic bishops call for polio vaccine boycott

by Fredrick Nzwilli, Religion News Service | jul. 28, 2015

NAIROBI, KENYA – Roman Catholic bishops in Kenya have urged citizens to boycott a mass polio vaccination campaign unless the safety of the vaccine has been confirmed through scientific tests.

The oral vaccination campaign by the World Health Organization and UNICEF is scheduled to begin Aug. 1 in Kenya.

Ahead of the campaign's launch, the bishops questioned the safety of the vaccines, saying the manufacturer failed to provide requested information and the government disregarded the bishops' request for tests.
Rumors have a bad reputation

- Many rumors turn out to be untrue, others very true.

- Epidemics can be sparked, financial markets crashed and political leaders overthrown “just” because of a rumor.

- They can be serious, don’t brush them off as “not fact”
A parent hears rumors from other parents about several children bitten by a rabid dog. A teacher sees an unusually high number of children absent from school and hears that they all have similar symptoms. It could be a coincidence. It could be a local disease outbreak. Or it could be the first signs of an epidemic.

The Global Outbreak Alert and Response Network gathers global disease intelligence using a number of sources, such as ministries of health, WHO country offices and collaborating centers, laboratories, academic institutes, and nongovernment organizations. The Global Public Health Intelligence Network (GPHIN),

The team meets each morning to review reports and rumors, assess their epidemiological significance, and determine actions needed. The team creates a detailed report that is distributed electronically each day to specific WHO staff around the world. From 1998 to 2001, WHO verified 578 outbreaks in 132 countries.
• Rumors, whether right or wrong, are an indicator of the underlying belief systems, personal histories and socio-political environment around those who believe them.

• Whether they are fact or fiction, they can have tremendous impacts on people’s individual or collective behavior.
Listening to the rumours: What the northern Nigeria polio vaccine boycott can tell us ten years on

Isaac Ghinai\textsuperscript{a,b,*}, Chris Willott\textsuperscript{a}, Ibrahim Dadari\textsuperscript{c} and Heidi J. Larson\textsuperscript{b}

\textit{Global Public Health}, 2013

(Abbreviations: CDC = Centres for Disease Control and Prevention; G8 = Group of Eight; GPEI = Global Polio Eradication Initiative; OIC = Organization of Islamic Cooperation; AU = African Union; NPI = National Programme on Immunisation; JNI = Jama’atu Nasril Islam)

Figure 1. Interactions between global actors working to resume polio eradication in Kano State. Source: Kaufman & Feldbaum, 2009.
Key recommendations

- When introducing a new vaccine, think beyond the vaccine and the vaccination to consider the contextual history as well as current societal and political factors that could influence public perception.
- Sometimes the solution lies outside the vaccination programme.
- When countering a negative rumour or conspiracy, consider the "fertile ground" factors that make the rumour popular in the first place. Sometimes changing delivery strategies, or actors can dispel rumours, which are just one of other underlying issues.
- Religious figures can be strong allies for immunisation programmes, as they are invested in the well-being of their followers. When excluded, religious leaders can also become barriers to public confidence in vaccines. Do not dismiss public concerns just because they are based on faith instead of
Local Engagement in Ebola Outbreaks and Beyond in Sierra Leone

Containment strategies for Ebola rupture fundamental features of social, political and religious life. Control efforts that involve local people and appreciate their perspectives, social structures and institutions are therefore vital.

However, some of the current Ebola responses reflect problematic assumptions about local ignorance and capability. These sentiments are deeply rooted, having evolved with unequal power dynamics over long periods of time.

Recognising and supporting local resilience will be essential in successfully and sustainably engaging populations in effective Ebola responses.

Models of ‘communities’ and ‘community engagement’

The perception that people living in a similar geographical area make up a harmonious ‘community’ with a uniform culture has been thoroughly critiqued.
What can we do?
Measuring vaccine confidence: analysis of data obtained by a media surveillance system used to analyse public concerns about vaccines

Heidi J Larson, David M D Smith, Pauline Paterson, Melissa Cumming, Elisabeth Eckersberger, Clark C Freifeld, Isaac Ghinai, Caitlin Jarrett, Louisa Paushter, John S Brownstein, Lawrence C Madoff

Figure 2: Proportion of vaccine-related reports categorised as positive or neutral, by country
Based on analysis of all 10,380 reports. Of the 9,655 reports (93%) that mentioned a country or countries, 11,535 countries were mentioned. Countries about which there were fewer than ten vaccine-related reports are shaded grey. The world proportion (69%) is shown by the arrow on scale bar. Country border data are from the Global Administrative Areas database.

Heidi.Larson@lshtm.ac.uk
Abstract: Mobile, social, real-time: the ongoing revolution in the way people communicate has given rise to a new kind of epidemiology. Digital data sources, when harnessed appropriately, can provide local and timely information about disease and health dynamics in real-time; there is unparalleled potential for epidemiology. The observation of the spatiotemporal movements of millions of people during disease outbreaks [4], the rapid detection of an unusual respiratory illness in a remote village anywhere on the globe [5], the near real-time estimation of influenza activity levels [6,7], and the assessment of vaccination sentiments during pandemic preparedness efforts [8] are examples of realizations of this potential.
Media analysis around rumors which prompted Ebola vaccine trial suspension in Ghana (2015)

Timeline

Circles indicate exact numbers of critiques (red) and rebuttals (green) appearing daily. Line plots show a 7-day moving average, calculated to show overall trend in critiques and rebuttals per day. Numbered text boxes linked below the timeline show headlines appearing on the indicated date, representing significant events and arguments in the controversy. Refer to the numbered list of "Timeline Notes," right, for contextual and background information.
HOW TO STEWARD MEDICAL COUNTERMEASURES AND PUBLIC TRUST IN AN EMERGENCY

A Communication Casebook for FDA and its Public Health Partners

How the US Food and Drug Administration (FDA) and other US government officials convey information about medical countermeasures (MCMs) will affect uptake, compliance, and ultimately survival in the aftermath of a natural disease emergency or a chemical, biological, radiological, or nuclear (CBRN) attack. Moreover, effective communication regarding the potential to strengthen psychological resilience as well as engender public trust in science, government,
Best Practices for Communicating Risk in an Emergency

1) Incorporate communication experts, insights, and goals at the outset when developing emergency management policies. Embrace communication as an essential part of “front-end” decision-making rather than the mere function of sharing policy decisions at the “back-end.”

2) Conduct pre-event communication planning that identifies potential threats or hazards, outlines risk reduction approaches, recognizes the resources needed to implement them, and spells out the responsibilities of principal actors.

3) Build pre-crisis partnerships and alliances with other stakeholder entities to coordinate communication resources and activities, enlist their help in better understanding and reaching target audiences, and establish trusted links that can be activated during the crisis period.

4) Accept the public as a legitimate partner in managing an emergency. Recognize the public’s right to know the risks that it faces as well as protective actions that it can take, and plan for the prompt sharing of this information so that people can freely carry out their own informed decisions.

5) Listen to the public before and during the emergency. Find out what people know, think, or want done about risks, and use this to inform communication and emergency response planning. Acknowledge people’s concerns, even if they do not conform to scientific risk assessments. Put yourself in their place and adapt messages.

6) Communicate with honesty, candor, and openness. Be truthful to foster credibility with the public and the media. Relate the truth as it is known, even if it may reflect poorly on the agency, and be frank about the potential severity of any crisis. Promptly make information accessible. Convey information uncertainties, strengths, and weaknesses.
Best Practices for Communicating Risk in an Emergency:

7) Accept uncertainty and ambiguity. In an emergency, acknowledge the dynamism of the situation and the potential need to act before all the facts are known. Be prepared to explain the fluidity of conditions and the measures being taken to fill in the knowledge gaps. Address differing scientific perspectives and international variances as needed.

8) Communicate with compassion, concern, and empathy. Recognize the human dimensions of the emergency, acknowledge people’s distress and extend genuine sympathy and understanding.

9) Respect the unique communication needs of diverse audiences. Be mindful of differences in cultural background, immigrant status, education, technological adeptness, hearing and seeing abilities, and other factors that influence information uptake and processing. Use clear, non-technical language along with graphics to clarify messages; employ multiple language translations where appropriate.

10) Meet the needs of the media and remain accessible. Plan to work diligently with the media before and during an incident knowing that members of the public often rely on news outlets to learn about a crisis or risk.

11) Convey messages of self-efficacy. Provide specific information to the public on how to reduce any potential harm and what can be done to help others. Protective messages can reduce material harm as well as enhance morale by restoring a sense of control over uncertain and menacing conditions.

12) Monitor public responses and update communication efforts to meet people’s evolving information needs.
Vaccine trust and the limits of information

Understanding trust in local contexts is key to communication about vaccination

By Heidi J. Larson

Over the past decade, there has been growing recognition and increasing research around the phenomenon of vaccine reluctance and refusal (1, 2). More recently, there has been a flurry of articles on what is being referred to as “vaccine hesitancy,” depolarizing the earlier characterization of individuals or

Key messages

- Public concerns about vaccines are not merely about vaccine safety, but are also about vaccine policies and recommendations, vaccine costs, and new research findings.
- Public decision making related to vaccine acceptance is complex and is neither driven by scientific nor economic evidence alone, but is also driven by a mix of scientific, psychological, sociocultural, and political reasons, all of which need to be better understood.
- The internet and new forms of social media have not only allowed for rapid and ubiquitous sharing of information—and misinformation—but have also allowed new methods of self-organisation and empowerment of newly founded online communities that argue against or for vaccines.
- Although communication of positive, evidence-based information about the safety of specific vaccines and their benefit-risk ratios to the public is crucial, communication alone will not stop public distrust and dissent against vaccines.
- Levels of public trust in vaccines are highly variable and context specific. To sustain or restore confidence in vaccines, a thorough understanding is needed of the population’s—or subpopulation’s—specific vaccine concerns, historical experiences, religious or political affiliation, and socioeconomic status.
- Core principles to be followed by all health providers, experts, health authorities, policy makers, and politicians include: engagement with and listening to stakeholders, being transparent about decision making, and being honest and open about uncertainty and risks.
**OUR MISSION:**
Building a modular platform scalable for successful deployment of Ebola vaccines

**EBOla vaccine Deployment, Acceptance and Compliance**

- Community engagement
- Identification tools
- Mobile technology
COMMUNITY ENGAGEMENT, COMMUNICATIONS AND TECHNOLOGY IN EBOLA CLINICAL TRIALS

20-21 FEB 2017
DAKAR, SENEGAL

Provisional Agenda

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<tr>
<td>0900</td>
<td>Welcome</td>
<td>Dr. Heidi Larson (LSHTM) &amp; Dan Irvine (World Vision)</td>
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<td>Opening</td>
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<td>Ambassador George Hodgson (British Embassy, Dakar)</td>
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<td>0945</td>
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<td>David Nabarro (Former UN Special Envoy on Ebola)</td>
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Day 1 – 20th Feb 2017

Recommended Reading

Building the legacy of Ebola: Survivors, health systems, and a blueprint for research and development

ETHICAL CONSIDERATIONS FOR ZIKA VIRUS HUMAN CHALLENGE TRIALS

International Red Cross and Red Crescent Movement Ebola Strategic Framework January 2015

Key experiences of community engagement and social mobilization in the Ebola response


A Systematic Review of Ebola Treatment Trials to Assess the Extent to Which They Adhere to Ethical Guidelines
A social science team act as the ‘eyes and ears’ for the trial, listening to what individuals are saying about the study through ethnographic observation, clinic exit interviews, in-depth interviews with participants and key stakeholders, and focus group discussions. The social science team provide daily feedback to the community liaison team on any rumours or concerns circulating in the community, to inform prompt dialogue on the issue.
Power

Ethnographic observations following advocacy meetings within the community highlighted mistrust of “small” leaders within Kambia towards local authority figures post-Ebola, undermining their ability to mobilise their own communities.

Trust

- High levels of fear and mistrust seen during the Ebola outbreak, with rumours often reflecting broader anxieties.

Fairness

Participant recruitment in EBOVAC-Salone needed to balance the need for scientifically valid and representative results with the community’s perception of fair selection of volunteers.
“MSF made a big mistake. We advocated for an increase in beds for too long, and everyone listened to MSF. ...Instead of asking for more beds we should have asked for more sensitization activities”

MSF’s Ebola emergency coordinator in Guinea

Grand Imam of Guinea Taking New Role as Ebola Messenger
Current and historic examples speak to the importance of remembering time context – past, present and future.

and, finally,

Never, never, assume what is in the minds and emotions of people. And never forget that they can change.

Heidi J Larson
Director
The Vaccine Confidence Project
Heidi.Larson@lshtm.ac.uk
The State of Vaccine Confidence
Download the full report, including details of confidence challenges, strategies, research methods, and the Vaccine Confidence Index.

Confidence Commentary: What’s in a name? Whether Zika or Ebola, the name provokes anxiety and fuels rumours

Heidi Larson | 22 Feb, 2016

So here is a radical thought. The rumour phenomenon around what is causing the microcephaly among babies in Brazil is not all that crazy. The rumours themselves may seem a bit crazy, but the fact that – in addition to all the scientists – so many people have come to believe them is serious.