### **IMPACT & INNOVATION SERIES**

# **KEEPING THE TRUST:**

Targeting Communication Gaps and Driving Vaccine Confidence

Reflections from a Gathering of Unlike Minds



mmunization's remarkable success at saving lives and preventing disease begins to unravel when misinformation erodes public confidence in vaccine safety and efficacy. The 2011 Pacific Health Summit addressed this concern as the primary focus of its plenary session: "Trust, Risk, and Demand: How Do We Respond to Outbreaks of Anxiety?" The discussion assembled a diverse array of high-level leaders from government, academia, media, industry, and civil society.

Acknowledging that a variety of communication gaps have led to immunization crises in both the developed and developing worlds, Summit participants brought a wealth of experience to bear on the challenges and issues surrounding public confidence in vaccines.

Key questions discussed:

- What role does the media play in ensuring accurate coverage of immunization issues?
- How can social science help prevent crises in public confidence concerning vaccines?
- To what extent does full transparency about immunization practices inform public decisionmaking about vaccines?
- What are the most effective approaches and vehicles for mitigating misunderstandings when they do occur?

The discussion outlined the layers of nuanced communication necessary to maintain public confidence in vaccines, and addressed the unique voices and strengths of different sectors. Participants placed special emphasis on promoting accurate, two-way communication between journalists and scientists. Another outcome included a renewed call for social science to take the lead on identifying and addressing the underlying causes of mistrust in populations. The following pages present excerpts from exchanges among the many internationally renowned thought leaders in attendance.

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\* Dr. Muhammad Pate's comments were made when he was CEO of the National Primary Health Care Development Agency, Nigeria.



A 2011 Plenary Summary

### THE TRUTH CHAIN:

## **Examining Perspectives from Every Link**

ummit participants emphasized that to truly address vaccine and immunization concerns, health workers must be empowered at every level and given the appropriate tools to convey coordinated, accurate information. This shared commitment and responsibility comprise a "truth chain" that connects each stakeholder—from top levels of policy and government down to front-line health workers—as partners in an interrelated effort to uphold public faith in the efficacy of vaccines.

This section highlights vital links in the truth chain that were identified by Summit participants, and summarizes their conclusions and recommendations for various sectors based on important personal experiences and lessons learned.

"The reality is that we talked about the cold chain. But we've also got a truth chain and a trust chain. It has to start at the highest levels of the policymakers, the implementers, industry, academia, down to me, where I have to ask a mother to let me immunize her child."

Louis Z. Cooper,
Professor Emeritus of Pediatrics,
College of Physicians & Surgeons, Columbia University

### **Policy**

Participants noted that populations should ideally be able to rely on their governments to set a gold standard for messaging and information—to be clear and consistent about what is safe and appropriate vis-à-vis immunization. When public confidence in vaccines falters, trusted government representatives can help address suspicions by being accessible and available to the public and the media, as well as by being a credible filter for the information that passes between them.

#### Media

Many comments centered on the need for journalists to take extra care to ensure that their sources of information have appropriate credentials in the scientific community. Other stakeholders can support the media's ability to do this by developing resources that brief the media on vaccine and immunization science and assist journalists with locating the best possible sources for a story. This collaborative approach ensures that the media, often a key force in shaping public opinion, has access to the most current and reliable information.

### Science

Participants agreed that the science behind vaccines is an evolving discipline, and that targeted efforts to communicate new scientific developments and discoveries to the public are essential to maintaining faith in the safety and efficacy of vaccines. The discussion emphasized the value of partnerships between scientists and the media in order to ensure that accurate information regarding vaccines and immunization reaches the public in a timely and efficient manner.

### Industry

Participants identified industry as a critical partner in efforts to communicate about the ability of vaccines to save lives. Industry players can utilize broad communication networks and may find it useful to work with front-line health workers or other trusted voices to help spread key vaccine messages.



### Communities

A consensus emerged that the most influential and trusted voices often come from within local communities themselves, and that the support and buy-in of local leaders is vital to successful immunization efforts. Participants agreed that it is crucial to work with and through the leadership of communities, such as religious and other traditional leaders, to create understanding around the reasons for vaccination and its resulting benefits.

# Front-line Health Workers

Peer communication is of paramount importance in the truth chain. In the developing world, front-line health workers are often the most direct, and sometimes the only, source of health information for parents and communities. In many cases, they reflect the cultural and social values and preferences of the communities in which they work. Participants noted the critical need to empower them with appropriate and updated information and engage them in efforts to address trust issues. Securing their buy-in before launching local programs or campaigns is key to ensuring their support for the immunization process.

### **Doctor-to-Patient**

In urban, often more economically developed societies, doctors and pediatricians are go-to resources for credible information on immunization. Summit participants suggested moving toward a more proactive approach that engages parents before children are born, so that conversations around the importance of vaccines and immunization occur well in advance of the scheduled vaccinations.

# **REACHING EVERY PARENT, EVERY CHILD:**

### The Potential and Challenges of Mass Communication

How can mass communication media, such as the Internet and television, impact ongoing vaccine advocacy and education efforts?

### Sheri McCoy

New Media and Speed

One of the things that we see in today's environment is that a tremendous amount of information—not all of it reliable—goes global within split seconds. That can impact how people think about healthcare, particularly in regard to moms who are very concerned about their children.

### Philip Campbell

Target Parental Concerns

What we're talking about here are crises of confidence. They can be slow crises, or major, sudden crises. One thing that got me thinking about this subject was a piece of research in which somebody had looked at the cognitive maps in parents about vaccine risks, and they showed how activist websites successfully hit many red lights waiting to be lit up in the minds of parents.

### **Dorothy Esangbedo**

Monitor Misleading Information

There is a need for continuous monitoring of information by all those who are involved in immunization. A recent television advert about acetaminophen syrup in my country displayed a mother carrying a baby, and the mother complained that her baby developed a fever after being immunized. In the advert, she was advised to administer acetaminophen syrup to relieve the fever. I was disturbed about this type of negative remark about immunization, so the paediatric association requested the regulatory agency to review the information in the advert because we thought it could lead to reduced vaccine uptake in the country. Within a few days, the regulatory agency obliged and effected a change by instructing the removal of that section of the advert. Monitoring is a job that really involves all of us.

Communication gaps between scientists and journalists can often lead to the circulation of misinformation within communities. What are these gaps, and how can scientists and journalists work together to overcome these barriers?

#### Heidi Larson

Communicate Science As An Evolving Discipline

With trust issues, we haven't done a great job of communicating with the public about science. In the push to say that science is fact, we have not communicated well that scientific evidence can change with new research, and that's where we lose the public. All stakeholders have to do a better job of communicating that science itself is an evolving discipline.



### David Salisbury

#### Find the Right Experts

There is a perception among journalists that scientists are all of equal status, and all of equal knowledge. I say this mindful of the coverage that is given to the opinions of a person whose only appropriate qualification is a Ph.D. in micropaleontology, and yet she comments liberally on vaccine science.

Sometimes the qualifications of scientists, experts, doctors, or professors have little to do with their preparedness to give opinions, and that is not always perceived by the journalists who are seeking opinions. We have to have a much clearer way of communicating the issues and articulating who the right experts are that should be advising the media.

#### Mia Malan

# Mutual Understanding Through Two-Way Communication

As a journalist, I can't report on an issue like vaccines without the help of scientists. ... It's crucial that scientists themselves understand how the media operates, and how we work, because then they would be able to manage their publicity better. Often scientists don't understand those elements, which means that they simply don't end up in the media.

On the other hand, it's extremely difficult for journalists, especially in developing countries, where it's often not a person with a science degree that reports on science, to assess whether they are interviewing the right scientist. I think there should be some sort of help. The right scientists need to be put forward by someone, so if there's an outbreak of something, the government can say, "Here are four scientists to speak to."

#### Philip Campbell

#### Centers to Promote Informed Media Coverage

With regard to toolkits and how to build reservoirs of trust, we have an example now in several countries of something called a Science Media Centre. The Science Media Centre brings journalists together for long-range briefings about topics—what's coming down the line, what we know about a particular technology—as well as providing rapid responses when a story breaks.

Culturing that sort of understanding amongst the journalistic community is one key step. Doing the same with the networks of bloggers and other networks that are the equivalent—actually investing the time and effort to get people primed in areas that could turn hot at any moment—is an example to follow.

In what ways can the media aid, and help ensure widespread coverage of, effective immunization efforts?

#### Mia Malan

#### Media Oversight

I think the role of the media is very much to put pressure on government to get its distribution systems into place, and to ensure that there are resources for people so they have enough money to get to a clinic and receive a vaccine.

#### Muhammad Pate

#### Partners in Immunization

The media in Nigeria has been very effective as a partner in our effort to improve immunization. By helping monitor and report back where immunization efforts go well and where they don't, they assist in the effort to get more children immunized.



# TOOLS TO HELP MINIMIZE DISTRUST AND INCREASE PUBLIC CONFIDENCE

What role can social research play in understanding concerns about immunization? How can social science help us anticipate and address backlashes against immunization efforts?

#### Heidi Larson

#### Analyze Drivers of Distrust

The really big issue is the importance of stepping back and looking at the contextual and driving factors behind public confidence issues, because they're often forgotten. We look at the vaccine itself, and sometimes forget about the dynamics, the time, and the context. The polio vaccine boycott in Nigeria was not uniquely about polio in northern Nigeria. It was driven by contextual factors. I think that's where social scientists, including cognitive psychologists and anthropologists like myself, come in. A group of us are launching a center on this topic that will also look outside of the vaccines field at other types of scientific skepticism: genetically modified organism skeptics, AIDS denialists, climate change skeptics. There are dynamics in those areas that we can certainly learn from.

"We look at the vaccine itself, and sometimes forget about the dynamics, the time, and the context."

#### Heidi Larson

Senior Lecturer, Faculty of Epidemiology and Population Health, London School of Hygiene & Tropical Medicine

#### Benjamin Schwartz

#### Address the Root Causes of Collective Resistance

When we talk about development, we talk about ending poverty, ending hunger, and ending inequality. The solution isn't technological, nor is it simply strengthening the health system. If we want to talk about vaccinating that fifth child, I would suggest that the solution is addressing some of the cultural and social norms that keep that child from being immunized.

<sup>1</sup> The polio vaccine boycott in Nigeria was partially informed by a period of drug testing during a 1996 outbreak of meningitis in Nigeria. Perceived links between the drugs and several deaths created distrust surrounding drugs and vaccines administered by Western companies. During polio vaccination efforts in 2003, this experience, together with some traditional leaders' false assertions that the vaccines were meant to sterilize Muslim children, contributed to widespread refusals to accept polio vaccinations. See Heidi J. Larson, Louis Z. Cooper, Juhani Eskola, Samuel L Katz, and Scott Ratzan. "New Decade of Vaccines 5: Addressing the Vaccine Confidence Gap," *The Lancet* 378, (Aug 6-Aug 12, 2011): 531-532.



#### Muhammad Pate

#### Locate Critical Links in the "Truth Chain"

It's so important to have periodic social research to inform how a program has actually improved going forward. In Nigeria, there has been communication research with partners from the United States and other places that have helped identify communication gaps we're missing. In addition, social monitoring data ought to be kept by the delivery institutions. That set of data should be analyzed to show that noncompliance used to be a major issue in Nigeria, but that it has dramatically gone down as a result of traditional institutions, which resolved 65-70% of the noncompliance.

#### Lola Dare

# Equip Front-line Workers with Social Science Knowledge

Social science research is very important, and it should include providing capacity to front-line health workers to give information that is credible and factual. Part of the problem we've had in Nigeria is that front-line health workers were not equipped to be able to respond to communities and answer their questions. It's very important to do that as part of social research.









### THE LOCAL COMMUNITY

What roles do front-line health workers and other trusted health delivery figures play in minimizing distrust?

#### Sally Davies

#### Buy-In along the Frontlines

I watched the Wakefield disasters in MMR<sup>2</sup> unfold while working as a both a trained pediatrician and a hematologist. It was quite clear that the front line was not getting on the front foot at that point. I had an experience in trying to introduce a new treatment in my pediatric hematology clinic—when my patients wouldn't accept it and the science was clear, eventually I sat down with one I knew particularly well and said, "Why are you not taking my advice? You're doing everything else." And he said, "Because your nurse told me I shouldn't."

I discovered that the nurses hadn't bought into the science. And by the time I had explained it in different ways, they did buy into it, and then all the patients were running in for the treatment. Front-line nurses are very important.

### Sheri McCoy

# Leverage Trusted Figures in The Local Community

It's really important to think about the message and who is delivering it, and that may vary, depending on the local market and where the consumer or the mother is. A good example of this is the work that Mitch Besser started in Africa looking at mentor mothers. Mothers who were infected with HIV/AIDS had the most influence on other

mothers in terms of telling them, "Here's what you need to do for nutrition; here are medicines that are available; here's how you can care for your child." That's a great example of finding the most influential source to deliver the message.

#### Anuradha Gupta

#### Grassroots Infrastructure: Strength in Numbers

In a country the size and scale of India, where awareness is low, education is low, and 70% of the population is living in villages where exposure to media is highly limited, who builds trust is a critical question. We are looking at a cohort of 26 million children every year, and the children are not being brought to a facility: health services have to reach the village. In this situation, the auxiliary nurse-midwife is actually the messenger who builds trust in the community, and therefore the skill set and communication skills of those workers become extremely important.

We also have a very robust system of more than 800,000 Community Link workers—comprising community opinion or religious leaders—who are working at the grassroots level and are extremely effective at countering propaganda.

#### Muhammad Pate

# Credible Vehicles to Address Vaccine Confidence Issues

Traditional and religious institutions are very dear to [Nigerians'] hearts, and those are what they listen to. They ascribe certain legitimacy to them.

Recently in Nigeria, we looked at where people are getting their information. Television, newspapers—we assumed

<sup>2</sup>In 1998, a later discredited report by Dr. Andrew Wakefield in *The Lancet* linked the measles, mumps, and rubella (MMR) vaccine as a possible cause of autism. The article and publicity it received resulted in a drop in immunizations and vaccine confidence. Dr. Wakefield's article was retracted by *The Lancet* in 2010.



these were the sources. But that's not where they get their information. It's the radio, it's peer communication. It's usually institutions that are local—when the priests say something, people share it with their neighbors. When a traditional leader speaks about an issue, others listen to the message and then take it to somebody else. Tapping into those social networks is more effective than a media-based approach to selling immunization.

What does effective communication at the community level look like, in both the developing and developed worlds?

#### Anuradha Gupta

# Community Mobilization and Impact in the Developing World

It is the front-line health workers who really have to carry the onus of communication, because it is up to them to give credible, objective, effective information. Having said that, I think you really need to go beyond front-line workers, and actually create communicators at the community level.

In every village in India now, we have created a village health and sanitation committee, where you have a lot of people from the village community represented. The people who are organizing health and nutrition days generate the demand for immunization. Be it front-line workers or non-governmental actors, the end objective really has to be community mobilization, and communities have to finally have insights into their own issues.

#### Seth Mnookin

# Proactive Approaches to Immunization in the Developed World

We all agree that it's much harder to gain trust back than to keep trust. So much of the discussion surrounding the issue "It is the front-line health workers who really have to carry the onus of communication, because it is up to them to give credible, objective, effective information."

> Anuradha Gupta, Joint Secretary, Ministry of Health and Family Welfare, India

of safety and trust in vaccines has been reactive: answering questions and addressing fears after they come up. As a parent, the first conversation I had with the public health community, or with a doctor about vaccines, was when I had my child in my pediatrician's office and there was a needle in my pediatrician's hands. I was not equipped to process any new information at that point.

One thought that I've had is moving that discussion earlier, to the prenatal period. That would mean building into prenatal care a conversation that parents have with a provider—and I'm talking primarily about domestically and in the West now—about the importance of vaccines and the reasons for the current vaccine schedule. Then that conversation occurs at a time when parents can take in new information and think about it, as opposed to their feeling as if something is being forced on them.



### THE OPEN DOOR POLICY:

# Honest and Transparent Communication

In what ways is transparency surrounding the benefits and perceived risks of vaccines a key component in establishing trust?

#### Muhammad Pate

#### Transparent and Open Dialogue

Let's have an improved way of communicating the benefits of immunization. Because no father or mother who actually understands the benefit of a vaccine truly will say, "I don't want my child to get this vaccine."

I strongly believe that in the long run, being transparent will serve our interests more than not being transparent, both in terms of vaccines, as well as with the risks that are attendant with vaccination. If we are going to maintain the truth chain's] integrity, there is no way to do it without being fully transparent. But how that is communicated is very important. I don't think that you can have an obvious truth and then not disclose it, and expect that the truth chain will be maintained.

### Philip Campbell

#### How to Have the Difficult Conversations?

We've heard about the misreporting of risks, and dangers. But, of course, vaccines do have real risks. And so there is a real question: How do we talk about what the science is telling us about the risk in taking a vaccine?

"Let's have an improved way of communicating the benefits of immunization. Because no father or mother who understands the benefit of a vaccine truly will say, "I don't want my child to get this vaccine."

Muhammad Pate, Minister of State for Health, Nigeria

### Sheri McCoy

#### A Holistic Dialogue around Vaccines

I think we need to be very transparent about potential risks. Equally important, though, is to be very transparent around the benefits, and make sure that people have the facts on both sides. In some cases, we focus more on the risk side than the benefit side.



### Muhammad Ali Dhansay

Building Trust through Full Disclosure Of Information

Something that's peculiar to the United States, which is not done in South Africa, is that in TV adverts on drugs or medications, side effects are given at the bottom [of the screen]. Is that sort of information given to communities?

I can speak for my country only, and I would say the answer is no. In [South Africa], you have the huge problem of inequity and inequality, and also access to information.

#### **Anne Schuchat**

Set a Precedent for Clear, Open, and Honest Communication

In the United States, government public health agencies at the national, state, and local levels put a high priority on communication and outreach during the H1N1 pandemic. A lot of people spent a lot of time being available to the media and putting forward public health messages. The H1N1 pandemic was perceived as a national crisis. We worked to apply risk communication principles, including to be accessible and available, to address uncertainty and to highlight the idea that things would change and evolve. Foremost, we were trying to be honest, open, and empathetic. It was important that we maintained our credibility in an environment where messages were likely to shift as we learned about how the outbreak was evolving.

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