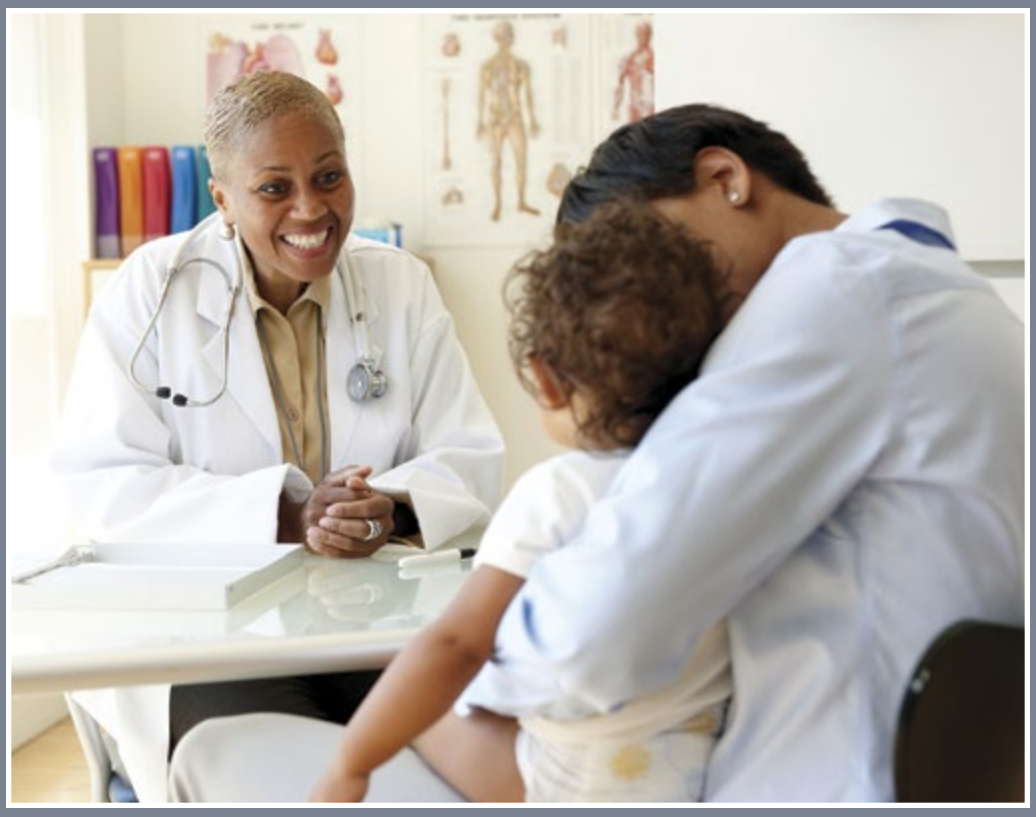
Public Trust in Vaccines: Defining a Research Agenda



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Public Trust in Vaccines: Defining a Research Agenda

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Preface

Recent headlines tell the story. "Measles rates triple in 2013 due to unvaccinated communities."[1] "Health officials urge vaccination in response to multiple chickenpox outbreaks."[2] Over the past half-decade, there have been scores of outbreaks of vaccine-preventable diseases caused by deliberately unvaccinated children.

After virtually eliminating many serious and sometimes deadly infectious diseases, the U.S. public health system has seen a recent increase in vaccine-preventable diseases. Growing numbers of parents are either delaying or selectively administering these vital immunizations—and a few are choosing not to vaccinate their children at all.[3] These trends reflect diminished public trust in the system that protects all of us against the timeless threat of communicable diseases—and the result is dangerous and costly outbreaks that are poised to grow worse in the future.

There is evidence that for some parents simply providing accurate information about vaccines is not enough. How can physicians, nurses, and other health professionals engage the growing ranks of "vaccine-hesitant" parents? And what is at stake if our public health and scientific leadership do not respond to this worrisome turn of events?

These questions get to the crux of the reshaped communication landscape we all face. It is no longer enough for scientists and federal institutions to issue recommendations; they also need to develop evidence-based communication strategies and implement them in consultation with those whom they are committed to protect. The expectation that experts will engage in a dialogue with citizens was addressed in a 2010 report of the American Academy of Arts and Sciences, *Do Scientists Understand the Public?,* which concluded that just as the public must be educated on scientific topics, so too must the scientific community be educated on public attitudes and opinions.[4]

Taking the 2010 report as its inspiration, the American Academy convened a workshop of leading researchers, practitioners, and policy-makers across

1. Centers for Disease Control and Prevention, "Measles—United States, January 1-August 24, 2013," *Morbidity and Mortality Weekly Report* (MMWR) 62 (36) (September 13, 2013): 741–743, http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6236a2.htm?s_cid=mm6236a2_w.

2. "Largest Chickenpox Outbreak in the U.S. Hits Vigo County in Indiana," *Huffpost Healthy Living*, November 27, 2011, http://www.huffingtonpost.com/2012/11/27/chickenpox-outbreak-largest-vigo-county-indiana_n_2199231.html.

3. Douglas J. Opel et al., "Social Marketing as a Strategy to Increase Immunization Rates," *Archives of Pediatrics and Adolescent Medicine* 163 (5) (May 2009): 432–437; doi: 10.1001/archpediatrics.2009.42.

4. Chris Mooney, *Do Scientists Understand the Public?* (Cambridge, Mass.: American Academy of Arts and Sciences, 2010), https://www.amacad.org/multimedia/pdfs/publications/researchpapersmonographs/scientistsUnderstand.pdf.

a range of disciplines, from anthropology and communications to pediatric medicine and public health. The goal was to delineate the types of research that would yield insights to inform evidence-based strategies for effective communication about childhood vaccination. The workshop, "Public Trust in Vaccines: Defining a Research Agenda," was held on September 26–27, 2013.

As the cochairs of the workshop, we are indebted to the workshop participants (listed on pages 13–15) and to the Academy staff who assisted with the organization of the workshop and the preparation of this report, notably John Randell, Dorothy Koveal, Nathan Yozwiak, Kimberly Durniak, Catherine McPherson, Hilary Dobel, and Phyllis Bendell. Madeline Drexler (Brandeis University and Harvard School of Public Health) served as rapporteur and provided an initial write-up of the workshop. We would also like to thank Duke University School of Medicine Dean Nancy Andrews and Institute of Medicine President Harvey Fineberg for their support and encouragement.

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Introduction

Years of research have shown that the decision to vaccinate one's child is rarely simple or straightforward. A welter of voices—in medicine, government, politics, media, churches, schools, and among one's family and friends—can confuse well-meaning parents who want to do the best for their offspring. Online forums, where appeals to emotion often drown out thoughtful discussion, also play a role in vaccination decisions.[5]

Larger social trends and policy decisions contribute to the mixed messages parents receive as well. Recent public health campaigns have been less likely to focus on vaccine-preventable diseases than on chronic, non-communicable afflictions, such as heart disease and obesity-related conditions, that are responsible for a majority of preventable deaths. Campaigns to make it easier to obtain philosophical or religious exemptions from state-mandated school entry vaccination requirements have been launched across the country. Finally, vaccines have become victims of their own successes: In the United States, many young parents have never encountered diseases such as polio, measles, rubella, and *Haemophilus influenzae* type b meningitis.

As a result, growing numbers of parents believe that vaccine-preventable diseases present a negligible risk. History has shown this to be a dangerously false assumption to make; what's more, nowhere is the dictum of thinking globally and acting locally more relevant than in discussing vaccine-preventable illnesses. Neither infectious diseases nor attitudes about vaccines pay heed to international borders. For the past several years, much of Western Europe has been suffering from a measles epidemic. The recent measles outbreaks in the United States are a direct result of this, as deliberately unvaccinated U.S. citizens were infected when traveling in Europe and then spread the disease once they returned home.[6] For more than forty years, American and European vaccine panics have fueled each other; since the advent of the Internet, these unfounded fears have spread to the far reaches of the globe.

5. Opel et al., "Social Marketing as a Strategy to Increase Immunization Rates"; Christina Dorell et al., "Factors That Influence Parental Vaccination Decisions for Adolescents, 13 to 17 Years Old," *Clinical Pediatrics* 52 (2) (February 2013): 162–170.

6. Centers for Disease Control and Prevention, "Measles—United States, January 1-August 24, 2013," *Morbidity and Mortality Weekly Report* (MMWR) 62 (36) (September 13, 2013): 741–743, http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6236a2.htm; Centers for Disease Control and Prevention, "Measles—United States, January-May 20, 2011," *Morbidity and Mortality Weekly Report* (MMWR) 60 (20) (May 27, 2011): 666–668, http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6020a7.htm.

For all these reasons, the American Academy organized a workshop to develop a research agenda outlining the types of rigorous studies that could yield evidence to help reconcile the emerging concerns of parents with the timeless goals of public health. Carrying out this scientific agenda will require engagement from an array of stakeholders: local, state, and federal government; NGOs; academia; foundations; and industry. Only with a cohesive vision and commitment can we avert a crisis-in-the-making.

Key Issues

From a public health perspective, the story of the twentieth century was, in many ways, the story of the success of vaccines. Smallpox, once a horrific scourge, was targeted by a global campaign that culminated in eradicating the disease in 1977. Today, the endgame of polio eradication is playing out in a small handful of nations where the disease remains endemic. In the United States, mandatory school vaccination laws have led to the virtual elimination of many deadly infectious diseases, including diphtheria, measles, mumps, polio, rubella, and *Haemophilus influenza* type b meningitis.

Looked at in one light, the country seems well positioned to continue these successes: The vast majority of parents in the United States immunize their children in accord with the recommended vaccine schedule. What's more, national surveys indicate that a majority of parents whose children are *not* fully vaccinated support immunization but are poorly served by the health care system due to factors including lack of access to primary care, lack of insurance coverage, inadequate medical treatment and follow-up, and failure to enforce school-entry immunization requirements.[7] (Addressing these issues will require fundamental changes in health care practices in this country and were therefore outside the scope of the Academy workshop.)

That leaves us with parents who are deliberately deferring or declining vaccines. Any clear-eyed assessment of the situation needs to acknowledge that their numbers are going up, not down. The results of this disturbing reality can be seen in costly outbreaks in communities with high numbers of deliberately unvaccinated children. In 2011, the nation experienced its largest number of individual measles cases (222 individuals) and outbreaks (17) since 1996; this is especially notable because the World Health Organization (WHO) declared measles eliminated from the United States in 2000. The index case in virtually every one of those recent outbreaks was an individual who was either deliberately unvaccinated—often a U.S. resident travelling abroad—or of unknown vaccine status.[8] We need only look to France to see how quickly a seemingly contained disease can spiral out of control: In 2007, there were 40 reported cases of measles infections in that country. That figure jumped to 600

7. Philip J. Smith et al., "Parental Delay or Refusal of Vaccine Doses, Childhood Vaccination Coverage at 24 Months of Age, and the Health Belief Model," *Public Health Reports* 126 (supplement 2) (2011): 135–146.

8. Centers for Disease Control and Prevention, "Measles—United States, 2011," *Morbidity and Mortality Weekly Report* (MMWR) 61 (15) (April 20, 2012): 253–257, http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6115a1.htm?s_cid=mm6115a1_w; Centers for Disease Control and Prevention, "Measles Press Conference: 50th Anniversary of Measles Vaccine," Press Briefing Transcript, December 5, 2013, http://www.cdc.gov/media/releases/2013/t1205-measles-threat.html.

in 2008—and rose to more than 15,000 in 2011.[9] Six of those cases resulted in death. Translating that rise to a population the size of the United States' gives you more than 70,000 measles infections—and an estimated public sector cost of hundreds of millions of dollars.

The recent measles outbreaks in the United States and Western Europe are especially tragic because the MMR vaccine is overwhelmingly effective, which means virtually every single one of those cases could have been prevented. (Measles continues to claim some 158,000 lives annually, or about 430 lives every day, with most victims under the age of five. More than 95 percent of deaths occur in low-income countries with weak public health infrastructures.[10])

And it is not just measles that is on the rise: In 2012, 48,277 cases of pertussis (whooping cough) were reported to the federal Centers for Disease Control and Prevention (CDC)[11]—the largest number in more than half a century, up from a modern low of about 1,000 cases in 1976.[12] In developing countries, hard-won advances can vanish in a blink of an eye: After one state in Nigeria ceased universal polio immunization in 2003 because of spurious fears that the vaccine was being used to sterilize Muslims, the disease was reintroduced to twenty previously polio-free countries within three years.[13]

Research has clearly shown that parental attitudes toward vaccines fall along a continuum ranging from total acceptance to total refusal. When we define vaccine-hesitant parents not only as those who selectively vaccinate or delay some vaccines but also as those who have some misgivings about vaccines, a substantial number—between 20 and 30 percent—end up in this category.[14]

Today, the term "vaccine hesitancy" has gained acceptance, a shift in terminology that reflects not only this more nuanced understanding of parents' positions, but also the importance of engaging and supporting those whose attitudes are not on one end of the spectrum or the other. Constructive dialogue between providers and parents can promote informed decision-making and help public health professionals better understand the concerns underlying vaccine hesitancy.[15]

9. WHO Regional Office of Europe, *Immunization Highlights, 2011–2012* (Copenhagen, Denmark: WHO Regional Office for Europe, December 2, 2011), 9.

10. World Health Organization, "Measles, Fact sheet N°286," updated February 2014, http://www.who.int/mediacentre/factsheets/fs286/en/.

11. Centers for Disease Control and Prevention, "Pertussis Outbreak Trends," updated September 2013, http://www.cdc.gov/pertussis/outbreaks/trends.html.

12. National Institutes of Health, "How To Whip Whooping Cough," *News in Health,* June 2013, http://newsinhealth.nih.gov/issue/jun2013/feature2.

13. World Health Organization, "Poliomyelitis in Nigeria and West/Central Africa," *World Health Organization Global Alert and Response*, June 18, 2008, http://www.who.int/csr/don/2008_06_18/en/.

14. Douglas J. Opel et al., "Development of a Survey to Identify Vaccine-Hesitant Parents," *Human Vaccines and Immunotherapeutics* 7 (4) (April 2011): 419–425, doi: 10.4161/hv.7.4.14120, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3360071/.

15. Heidi J. Larson, "Negotiating Vaccine Acceptance in an Era of Reluctance," *Human Vaccines and Immunotherapeutics* 9 (8) (July 29, 2013): 1779–1781.

WHY DO PARENTS SAY NO?

Recent history shows the devastating effects of inaccurate information about vaccines. In 1998, press coverage of British physician Andrew Wakefield's specious claims linking the MMR vaccine to bowel disease and autism caused public confidence in the vaccine to plummet. In England, MMR coverage rates dropped from nearly 93 percent in 1997 to 79.9 percent in 2003–2004.

And once doubt is planted, it is hard to uproot. In a 2011 survey taken immediately after the Wakefield study was retracted and Wakefield was accused of fraud, 27.9 percent of respondents said they still believed there was a link between vaccines and autism. In a stark illustration of the fact that simply restating a discredited fear can cause people to believe it is true, 5.6 percent of respondents said they were convinced that there was a link between vaccines and autism only *after* the news reports discrediting Wakefield's study as fraudulent were aired.[16]

What else drives the vaccine confidence gap? Surveys and studies point to a myriad of reasons that parents request non-medical exemptions. Some are so unfamiliar with the diseases vaccines protect against that they conclude the vaccines themselves are unnecessary. Others cite concerns with vaccine safety broadly or rare vaccine side effects specifically, while questioning the efficacy of giving vaccines to healthy people in the first place. Some believe that vaccines overload children's immune systems, or that "natural immunity" is preferable to vaccine-induced immunity; others believe that their children can avoid vaccination because a high enough percentage of the population is vaccinated to keep a given disease at bay. (Choosing not to vaccinate for that reason was described by one popular anti-vaccine doctor as "hiding in the herd."[17]) Some parents cite their belief in alternative medicines; others are distrustful of the medical system, science, or anything recommended by government in general.[18]

On a more individual level, social science has shown that individuals have different styles of decision-making. Some parents accept social norms; others are more apt to rely on doctors, parents, or friends for advice. There are also those who scour the primary academic literature in an attempt to understand the science behind vaccines.[19]

16. Daniel J. DeNoon, "WebMD Survey: Safety Biggest Vaccine Worry for Parents," *WebMD*, March 31, 2011, http://children.webmd.com/vaccines/news/20110329/webmd-survey-safety-biggest-vaccine-worry-parents?page=2.

17. Robert Sears, *The Vaccine Book* (New York: Little, Brown, 2007), 96–97.

18. J. S. Rota et al., "Processes for obtaining non-medical exemptions to state immunization laws," *American Journal of Public Health* 91 (2001): 645–648; Heidi J. Larson, "Public Trust in Vaccines: A Global Perspective," The Vaccine Confidence Project, London School of Hygiene & Tropical Medicine, presented at Public Trust in Vaccines: Defining a Research Agenda, September 26, 2013.

19. Emily K. Brunson, "How Parents Make Decisions about their Children's Vaccinations," *Vaccine* 31 (46) (November 2013): 5466–5470.

It is also important to remember that decisions about vaccination are not made at a single point in time. Many parents have indicated that they began mulling the issue even before deciding to have a child. Pregnancy—a time of active information seeking—appears to be an especially formative time for thinking about vaccination.

THE SOCIAL GOOD

As experts focus on the reasons why parents are reluctant to immunize their children, it is important to note the reasons they *do* opt for vaccination. While the main reason parents endorse vaccination is to protect their own children, protecting the community is also a salient rationale. A 2012 review article found that while only 1–6 percent of parents spontaneously name benefits to others as a primary reason to vaccinate, some 30–60 percent agreed with that assessment when asked if it is an important reason to vaccinate.[20]

In other words, the altruistic motive to vaccinate may be stronger than is widely assumed—an untapped area of research that could yield new approaches to public persuasion.

THE CLINICAL CONVERSATION

One of the liveliest workshop discussions focused on the importance of the vaccine conversations that doctors, nurses, pharmacists, and other providers have with parents—both because it is a time when parents can receive accurate information and because it is a chance for providers to gain insight into parents' vaccine knowledge, attitudes, and beliefs.

Workshop participants discussed the types of research that would help physicians best prepare for this conversation. Is one type of vaccine-hesitant parent more likely to respond to an argument about societal obligations while another type responds most strongly to a discussion of the diseases themselves? Is there any way to identify vaccine-rejecting parents whose minds will never be changed?

Workshop attendees also discussed a finding that has emerged from recently published research: Parents who are told by providers what vaccines their children will get are less likely to resist those recommendations than parents whose providers ask them for their input on vaccines.[21]

20. Maheen Quadri-Sheriff et al., "The Role of Herd Immunity in Parents' Decision to Vaccinate Children: A Systematic Review," *Pediatrics* 130 (3) (September 1, 2012): 522; originally published online August 27, 2012, doi: 10.1542/peds.2012-0140.

21. Douglas J. Opel et al., "The Architecture of Provider-Parent Vaccine Discussions at Health Supervision Visits," *Pediatrics* 132 (6) (December 2013): 1037–1046; published November 4, 2013, doi:10.1542/peds.2013-2037.

A Proposed Research Agenda

CENTRAL PROBLEM

Over the past two decades, a combination of fraudulent scientific studies, irresponsible reporting, and well-meaning but misinformed citizen activists has led to a steady increase in the proportion of parents who have concerns about the recommended childhood vaccine schedule. While overall vaccine uptake rates in the United States remain high, these concerns have resulted in a significant expansion in the number of parents who are delaying, and in extreme cases even refusing, vaccines for their children.

These actions have led to outbreaks of vaccine-preventable diseases: The largest domestic measles outbreak of the past 15 years occurred in 2013, and 2011 and 2013 were the two years with the highest number of domestic measles infections since the 1990s. All of the measles outbreaks in 2013 were caused by infections that originated outside of the country—and the overwhelming majority of the secondary infections occurred in deliberately unvaccinated children or infants too young to be vaccinated. The human and economic costs of these outbreaks are worthy of attention; one recent study estimated that the public sector cost of containing a *single case* of measles is more than $10,000.[22]

As the scope of the problem has become more apparent, the public health and medical communities have begun to examine the best ways to communicate with anxious or wary parents. There has not, however, been a concerted effort to develop an evidenced-based toolkit to guide these discussions. The following suggested areas of research would provide the necessary data for such an effort.

22. David E. Sugarman et al., "Measles Outbreak in a Highly Vaccinated Population, San Diego, 2008: Role of the Intentionally Undervaccinated," *Pediatrics* 125 (4) (April 1, 2010): 747–755; originally published online March 22, 2010, doi: 10.1542/peds.2009-1653.

CORE ISSUES AND RECOMMENDATIONS FOR RESEARCH

1. Parental Attitudes and Knowledge

- When and how are attitudes and beliefs about immunization formed?
  - How do parents learn about vaccines? Where do they encounter vaccine information, and how are they influenced by messages from expert and non-expert sources?
  - How does the perception of the benefits to the individual versus the community shape a parent's decision to vaccinate his or her child?
  - To what extent does vaccine hesitancy result from a broader distrust in government and science?
- When are prospective parents or parents of infants most receptive to information about vaccines (e.g., during prenatal care visits, at the first well-child visit, etc.)?

Answering these questions will require longitudinal studies within individual communities to assess how and when parents arrive at vaccination decisions, how their attitudes and beliefs change over time, and what information sources (e.g., primary care physicians, Internet/television, social media, local social networks, family and friends, etc.) most strongly influence their decisions. These studies should sample prospective parents in young adulthood, expectant parents during pregnancy, parents immediately after the birth of their children, and parents when their children are scheduled to receive recommended vaccines.

2. The Medical Encounter

- How can providers best determine parents' attitudes about immunization?
- How can providers best respond to parental concerns?
- How can providers best present their science-based vaccine recommendations?
- Could a "checklist" for providers be developed to improve communications with parents?

Researchers should evaluate the effectiveness of communication strategies, including negotiation, used by all clinicians when discussing childhood vaccination with parents. A clearinghouse of vaccination-related interventions and innovations, drawing on data from state and local immunization managers and from other countries, and how these interventions affect uptake of childhood vaccinations, would facilitate such studies.

3. At-Risk Communities

- What are the most effective ways to identify geographic communities at increased risk of vaccine-preventable disease outbreaks?
- Are there common features among these communities?
- Do social networks play a different role in these communities than in communities at lower risk for vaccine-preventable disease outbreaks?
- How does peer-to-peer communication influence vaccine acceptance and uptake?
- In the case of communities or demographic groups that are apt to delay or refuse childhood vaccinations, what types of community-based interventions would have the largest effect on vaccine uptake?

A CALL FOR ACTION

Childhood vaccination is a cornerstone of a healthy society—an essential bulwark against infections that, though currently in the shadows, inevitably reappear when public health defenses are down. In the United States, overall childhood vaccination coverage is still strong. But recent increases in immunization delay and refusal—and the resulting cases and outbreaks of preventable diseases—are a harbinger of danger.

Reversing this situation will require that public health leaders develop and promote evidence-based actions to increase the optimal use of vaccines. Therefore, it is critical that government agencies and private foundations support and prioritize cross-disciplinary research on immunization decision-making, as well as evaluate the effectiveness of health communication strategies. The research agenda presented here provides a foundation for enhancing both parent-provider and health agency communication. At stake is not only the physical health of the U.S. population, but also our nation's basic trust in science-based public health recommendations. A modern and well-functioning society can afford no less.

Workshop Participants

Public Trust in Vaccines: Defining a Research Agenda

September 26–27, 2013
Cambridge, Massachusetts

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