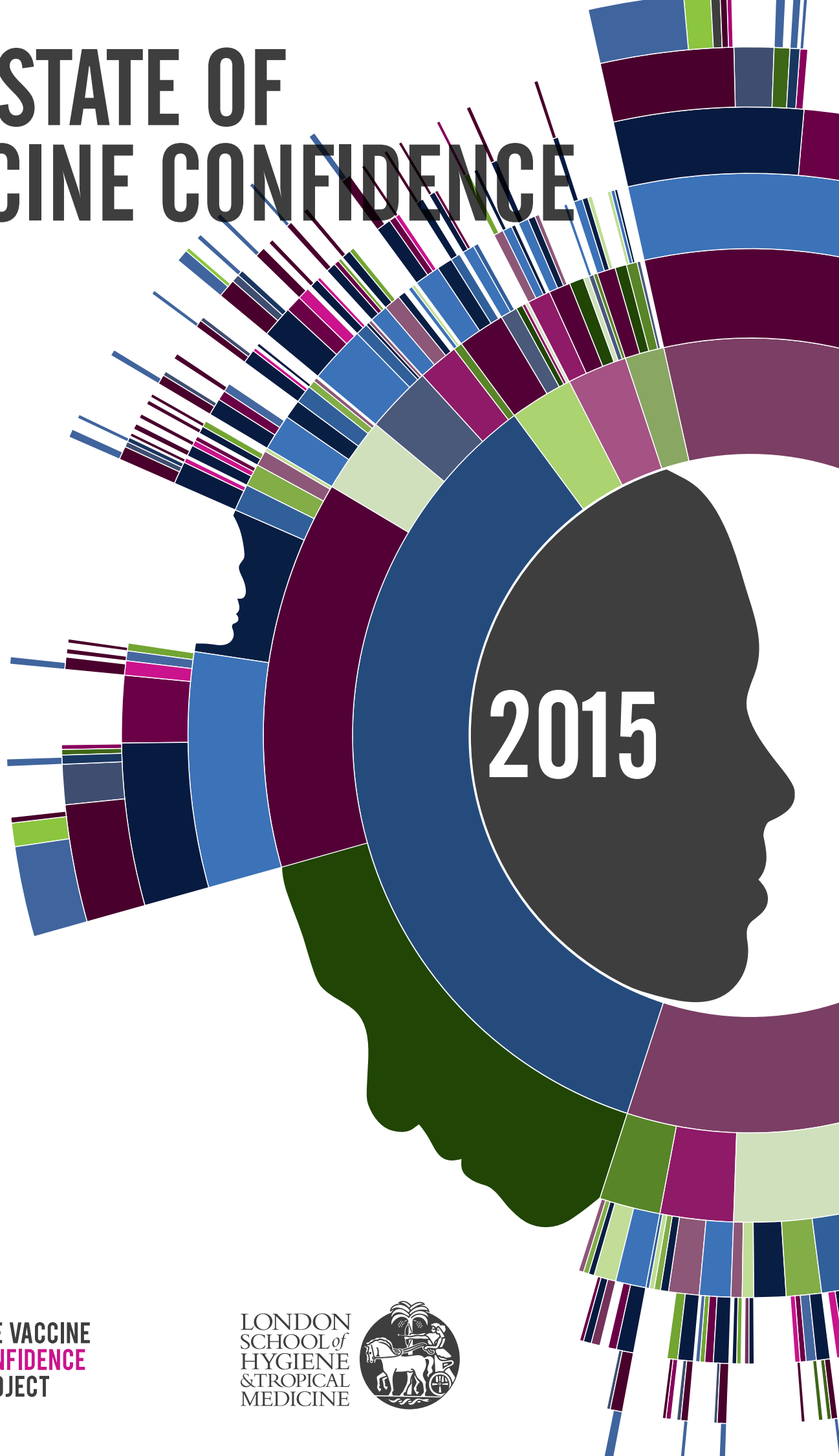


THE STATE OF VACCINE CONFIDENCE



THE VACCINE
CONFIDENCE
PROJECT

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



The State of Vaccine Confidence 2015



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Contents

Preface	7
Chapter 1: Introduction: Why is this report relevant and necessary now?	9
Chapter 2: Confidence challenges and successes over the past decade	13
Chapter 3: Measuring vaccine confidence: No single metric tells the story	21
Conclusion and recommendations	36
Boxes	
Chapter 1	
Vaccine confidence: A global overview	9
Chapter 2	
DR Congo case study: An anti-vaccination religious leader becomes a quiet advocate	14
The example of MenAfriVac: An inspiring success story that built confidence	15
Global polio eradication: The precariousness of progress	16
Tetanus toxoid and the Catholic Church: The persistence of a rumour over two decades	17
Chapter 3	
Bringing together fast and slow data to understand the vaccine confidence phenomenon	21
Gallup poll shows both changed and persistent public perceptions of vaccines	28
The 2009 H1N1 pandemic: A lesson for the future?	30
What is the Vaccine Confidence Index?	30
Conclusion and recommendations	
Protecting Public Trust in Immunisation: Some key recommendations	37
Public Trust in Vaccines: Defining a research agenda	37

Tables

Chapter 2

Table 1: Coverage for tetanus toxoid in the Philippines 1987–1996	17
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Chapter 3

Table 1: Survey size and prevalence of hesitancy and refusal	23
Table 2: Nigeria state-level analysis of prevalence of hesitancy and refusal	26
Table 3: Reasons for hesitancy categorised by Confidence-Convenience-Complacency	26
Table 4: Topic of coded measles tweets, retweets, social media and news articles	32

Figures

Chapter 1

Figure 1: 'A warning from history': How the polio virus escaped the GPEI	10
Figure 2: The global rise of vaccines since the launch of EPI	11

Chapter 2

Figure 1: Poliovirus cases in India 1995–2012	13
Figure 2: MenAfriVac impact on meningitis cases	15

Chapter 3

Figure 1: Fast and slow data monitoring cycle	21
Figure 2: Relationship between hesitancy and confidence in immunisation services	22
Figure 3: Vaccine-hesitant parents and their reasons	24–25
Figure 4: Importance of vaccination	28
Figure 5: Cervical cancer incidence rates worldwide	29
Figure 6: The global spread of HPV rumours	29
Figure 7: Comparison of relative proportions of weekly tweets, social media messages, and online news articles to measles cases from April 15 to November 11, 2013	32

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“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

Preface

The power of belief

This report and the research behind it has evolved over the past decade. In August 2003, when five states in northern Nigeria launched a boycott of polio vaccination, which Kano State sustained for eleven months, few could have imagined the longer term global impacts and costs to the Global Polio Eradication Initiative.

There were no specific vaccine-related adverse events or safety issues that sparked the boycott, it was "just" rumours fuelling fears of sterilisation, albeit fuelled by deeper political issues both local and geo-political. It was not really about the polio vaccine, it was not even about the polio vaccination initiative, which merely offered a high-visibility platform, a stage for other dramas well beyond the immunisation programme.

At the time, I was leading UNICEF's global communication for immunisation, initially focusing on the introduction of new vaccines, but increasingly called on to manage confidence issues around both new as well as "routine" vaccines. I quickly learned there was nothing routine about vaccines and immunisation. While the Nigeria polio vaccination boycott made the headlines, there were many smaller, albeit also damaging, pockets of vaccine questioning and resistance around the world. Some of the vaccine anxieties were driven by reports of adverse events following immunisation, some were fears among marginalised populations whose years of marginalisation made them more prone to suspicion of government programmes, other resistance came from elites who subscribed to natural remedies or just felt they just didn't need vaccines – the overconfident, and yet others were driven by political, religious or self-appointed leaders with an agenda beyond the vaccine or immunisation programme, as in Northern Nigeria. When I put my anthropology hat on and considered their points of view, some of the concerns and questions I heard were actually not unreasonable, they were more about other felt needs and priorities, or other notions of what they felt was best for their children. The people expressing their concerns were not "ignorant". As one angry group of mothers told me in Kano State, "We would not be asking these questions if we were 'ignorant'" (as they were being referred to on the radio).

The old adage "educate a mother, save a child" has become less compelling in the case of vaccination decisions. Some of the most educated mothers in the world – including elites in low and middle-income countries – are the ones questioning and refusing vaccines. These debates are not based on not having enough information, they are about alternative notions of immune systems, naturopathy, or other "evidence" – sometimes inaccurate – that has been collected from the internet or through social networks that raise and reinforce concerns about the safety and relevance of a particular vaccine(s). These mothers are not generally "anti-science", but in fact demanding more science, and more evidence, on the long term safety of vaccines. Whether they are mothers taking

their children to Disneyland, or mothers in northern Nigeria, if they decide to delay or refuse a vaccination, they are not doing it with an intent to compromise their children's health. These parents make choices which they genuinely believe are the best for their child.

One of the complicating factors in the vaccine confidence landscape is the role of health providers. They are, on the one hand, still one of the strongest influencers for a parent's vaccination decisions, yet, at the same time, there are more and more reported instances of health providers themselves being hesitant about one or multiple vaccines. Recent research has additionally shown that even among health providers who are positive about vaccines, they may accommodate a parent's request to delay a vaccination in order to keep the trust relationship with the family.

We have studied similar dynamics in the relationship between politicians and their publics, where politicians sometimes disregard scientific advice to appease the concerns of their constituencies, again to keep a trust relationship for a much wider remit of issues than immunisation.

We cannot forget the importance of trust relationships that exist in the lives of individuals and communities well beyond immunisation programmes. These are personal, professional and political histories and relationships that can make or break an immunisation or other health programme.

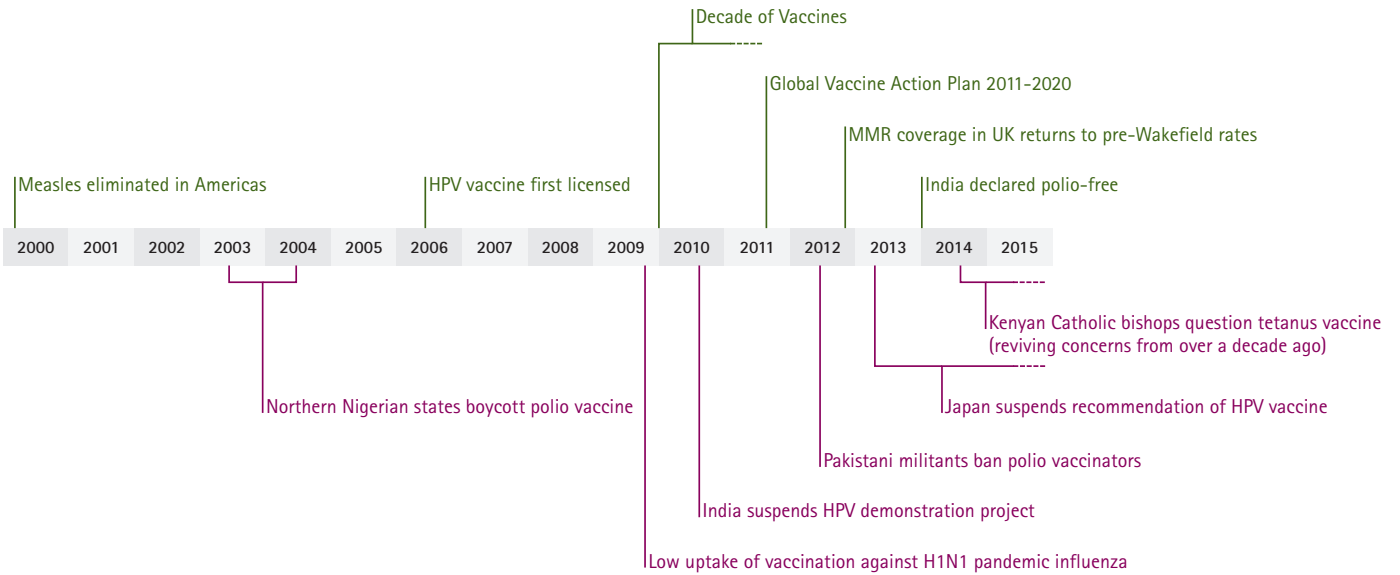
Consider the West Africa Ebola outbreak and response, where a history of violence and conflict left scars of deep distrust in the population, many of whom initially refused Ebola control measures such as quarantine and "safe" burials, denied the existence of the Ebola virus, and even killed some health workers. Conflict and insecurity can also affect people's trust in each other, and in society generally. In the Ebola affected context, routine immunisation plummeted due to a strained health system as well as fears of injections, creating new anxieties about widespread measles outbreaks.

Current and historic examples, a number of which are discussed in this report, speak to the importance of remembering time context – past, present and future. Remembering the experiences, influences and lessons of the past, being aware of present contextual dynamics that can impact on the delivery and acceptance of vaccines and immunisation programmes, and, finally, being alert to the longer term implications of our actions – or inactions – today, are all key.

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

Timeline: Major events in vaccine confidence over the past 15 years



Chapter 1

Introduction: Why is this report relevant and necessary now?

One decade on from the northern Nigeria polio vaccination boycott despite progress challenges remain

In July 2003, five states in Nigeria's predominantly Muslim north initiated a boycott of polio vaccination which persisted in Kano State for eleven months. The damage – short as well as longer term – was severe. The boycott, driven by rumours and distrust, quintupled polio incidence in Nigeria between 2002 and 2006, seeded polio outbreaks across three continents (Figure 1), and cost over US\$500 million.¹

The boycott and its impacts were a wake-up call to the immunisation and global health community as to the power of seemingly benign rumours to disrupt, not only a local immunisation programme, but a global eradication initiative.

The good news is that the boycott prompted extensive community engagement, ongoing listening and dialogue, trust building with religious and traditional leaders and an overall strengthened polio programme. By early March 2015, Nigeria had reported no wild polio cases in the previous seven months.

At the same time as Nigeria was facing the polio vaccine boycott, India was also challenged by pockets of community resistance to polio vaccination. However, with similar strategies of trust building with local communities and partnering with

local trusted institutions, India made tremendous strides and successfully eliminated polio, being declared polio-free in January 2014. Both Nigeria and India have shown that confidence challenges can be overcome.

Today, against the overall progress, there are persisting as well as new challenges ahead facing polio eradication as well as other immunisation initiatives. These challenges range from security threats and violence in some settings to personal perceptions of risk in others. All point to the importance of building public trust and confidence. Public trust is dynamic and responsive to changing social and political dynamics and needs to be continually renewed. Without it, even the best science and public health strategies can become futile.

This report analyses a number of vaccine confidence issues and the paths to their resolution over the past decade, including and beyond polio. It also presents options for monitoring and measuring public confidence to detect waning confidence early and identify issues of concern, as well as reporting on strategies that have had positive impacts in engaging populations to build trust and confidence.

While public confidence is a linchpin of successful immunisation programmes, the importance of provider confidence and political confidence can also not be understated. Throughout this report there is a theme of the dynamic and interactive domains of public, provider and political confidence, not just their respective confidence in vaccines, but mutual confidence between publics, health providers and politicians. Any missing link in this fundamental trust chain can undermine the overall success of immunisation. The State of Vaccine Confidence Report also marks the launch of a new global collaboration between the London School of Hygiene & Tropical Medicine and Gallup International to routinely monitor public confidence in immunisation globally. Inspired by the Consumer Confidence Index developed by the University of Michigan, we introduce a Vaccine Confidence Index to capture public confidence in national immunisation programmes and government services more broadly, confidence in vaccines generally, and identify hesitancy around any specific vaccines. It queries whether initial hesitancy to vaccinate actually has led to vaccine refusal. In Chapter 3, we present the results of the first five countries surveyed. These country surveys will be expanded globally, updated by country, repeated over time and published in a global vaccine confidence report.

EPI: 40 years later

There have been great successes in vaccination worldwide. The Expanded Programme on Immunization (EPI) was launched

Vaccine confidence: A global overview

Perceptions of vaccine risks are highly varied, as are the influences of risk perceptions – such as safety concerns, religious and ethical beliefs and politics – which vary between countries and regionally, over time, by vaccine.

In 2013 the World Economic Forum highlighted "digital wildfires in a hyper-connected world" and "the dangers of hubris on human health" as dominant global risks.¹² The Internet has fuelled the ability of like-minded people to share their common issues; whether for, against, or indifferent about vaccination.

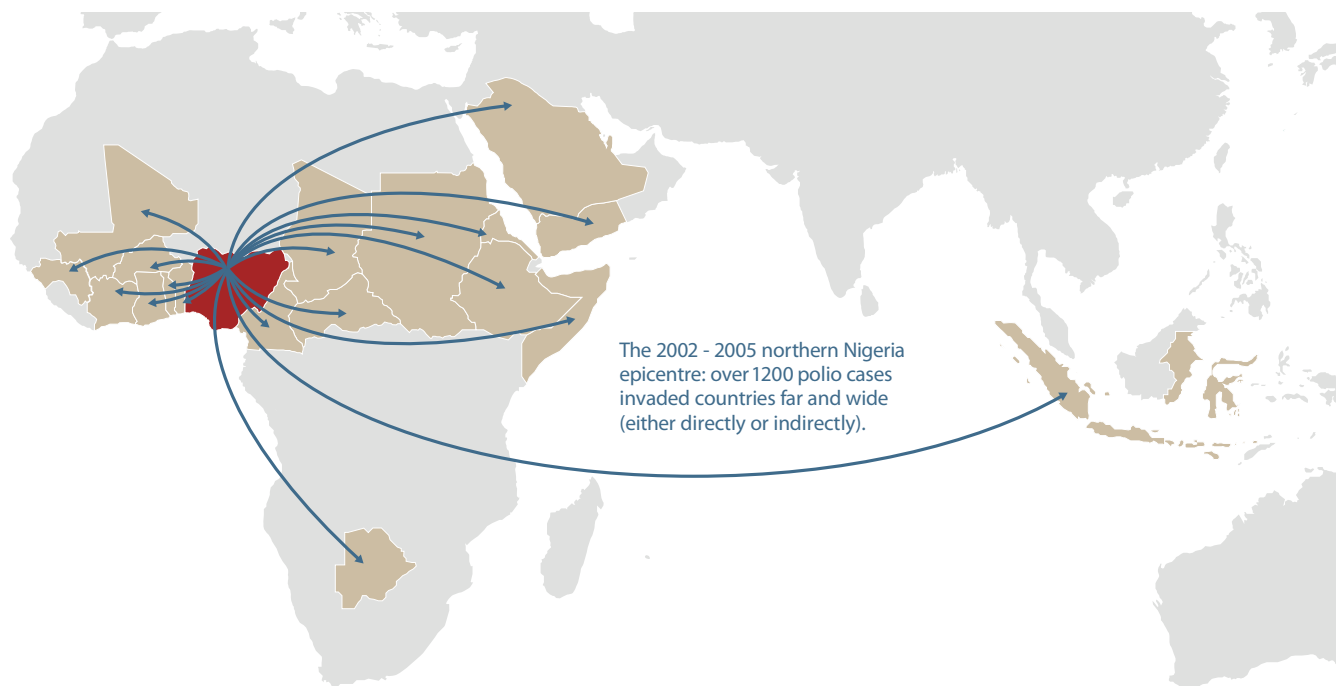
Vaccination hesitancy is just one of many reasons for non- or under-vaccination. The causes and impacts of vaccine hesitancy are complex and context-specific. There is no single cause of hesitancy that can be easily addressed by a simple intervention or activity.

Risk expert Paul Slovic writes about risk as feelings (fast, instinctive, emotional), risk as analysis (logic, reason, scientific) and risk as politics.¹³

For too long the public health community has neglected the importance of recognising the "risk as feelings" domain.

Science matters, and it is an absolutely crucial foundation for every aspect of ensuring safe and effective vaccines. But it is not enough.

Figure 1: ‘A warning from history’: How the polio virus escaped the GPEI



Published originally in the November 2012 Report of the Independent Monitoring Board of the GPEI, this figure presents the spread of poliovirus from Nigeria following the 2003–2004 boycott. The IMB aptly titled its figure “A warning from history.”

Source: IMB. 2012. Sixth Report of the Independent Monitoring Board of the Global Polio Eradication Initiative: November 2012. Page 11. Available at: http://www.polioeradication.org/Portals/0/Document/Aboutus/Governance/IMB/7IMBMeeting/7IMB_Report_EN.pdf [Accessed 19 March 2015].

four decades ago with the goal of expanding global access to vaccines against six diseases: diphtheria, whooping cough (pertussis), tetanus, measles, poliomyelitis and tuberculosis. At the start of the EPI effort in 1974, DTP3 coverage was only 20%; today it is 83%. Since then, nine other immunisations have been added to the global immunisation agenda: hepatitis B, haemophilus influenza B (HiB), pneumococcus, rotavirus, human papilloma virus (HPV), yellow fever, meningococcal A meningitis, Japanese encephalitis, and rubella.⁴ There has been particular progress in the global introduction of hepatitis B over the last decade.

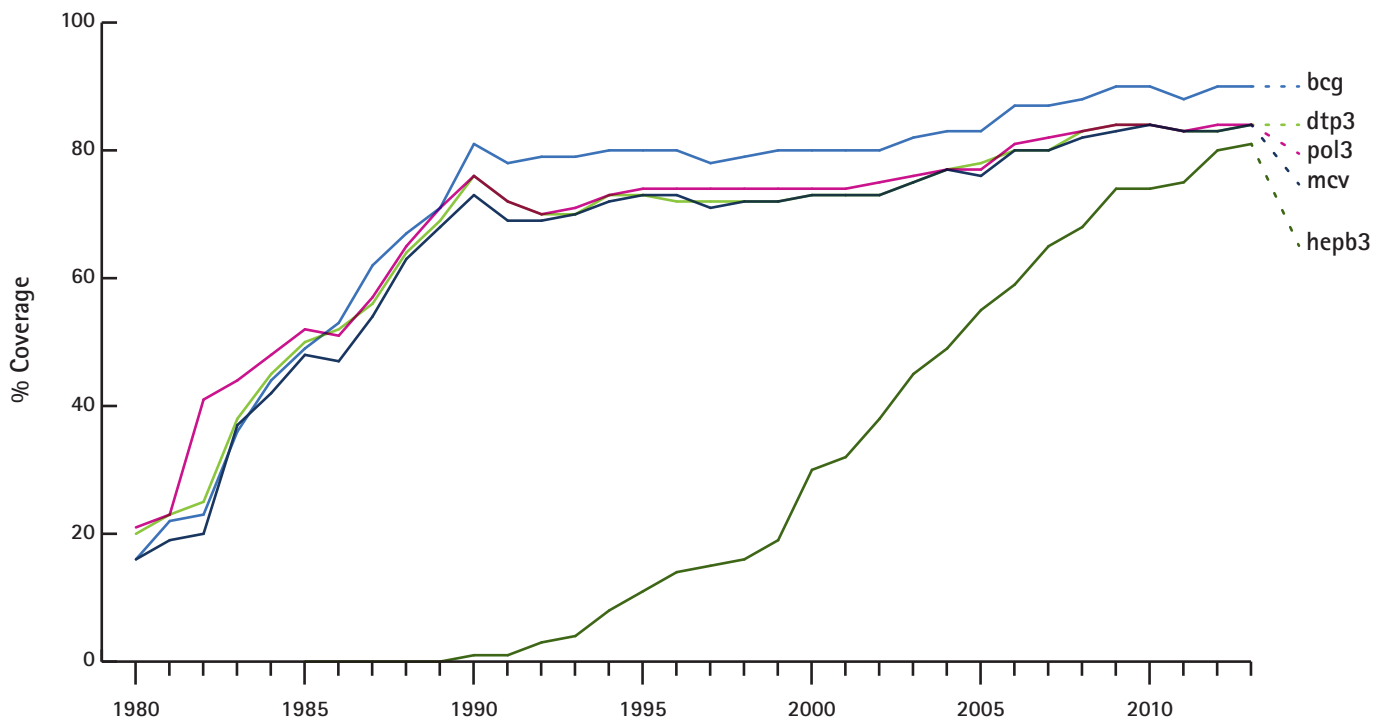
Increased attention to the issue of vaccine hesitancy and its risks for public health

Despite the overall success in immunisation coverage, including the introduction of new vaccines, there has been growing attention to vaccine hesitancy by national governments, international organisations and the research community. In addition to the public confidence challenges faced by the Global Polio Eradication Initiative in some settings, episodes such as the globally low public acceptance of vaccination against the 2009 H1N1 pandemic influenza signalled the need for trust building to overcome what has been referred to by public health experts as “a crisis of public confidence in vaccines”.⁵

In March 2013, the World Health Organization (WHO) Strategic Advisory Group of Experts on Immunization (SAGE) appointed a Working Group to address Vaccine Hesitancy tasked with developing:

- 1) A definition of vaccine hesitancy and its scope;
 - 2) Advice on how to address vaccine hesitancy and its determinants;
 - 3) A review of vaccine hesitancy in different settings and context-specific causes, its expression and its impact;
 - 4) Identification of existing as well as new activities and strategies to address vaccine hesitancy that could have a positive impact; and
 - 5) Indicators to measure vaccine hesitancy that could be used to monitor progress in the context of the “Decade of Vaccines” Global Vaccine Action Plan (GVAP).
- In the United States, the National Vaccines Advisory Committee (NVAC) has also established a Working Group on Vaccine Confidence.⁶ It has similarly been tasked with preparing a report on:
- 1) The determinants of vaccination acceptance among parents;
 - 2) Advice to Health and Human Services (HHS) on ways to improve parental confidence in vaccine recommendations; and,
 - 3) Ways to measure confidence in vaccines and vaccination to inform the design and evaluate the impact of interventions.
- In addition to these committees, a number of countries around the world are also exploring how to better identify vaccine confidence gaps and better understand the scale and nature of vaccine confidence issues and their impact on vaccine uptake. Since 2000, the volume of scholarly publications on vaccine hesitancy has nearly quadrupled,⁷ indicating increased knowledge production on the topic, and growing concern as to how this can disrupt immunisation programmes

Figure 2: The global rise of vaccines since the launch of EPI



WHO/UNICEF global coverage estimates for selected vaccines from 1980–2013, as of July 2014, presented as percentage of the target population that has received each vaccination.

Source: WHO. 2014. WHO/UNICEF estimates of national immunisation coverage.

http://www.who.int/immunization/monitoring_surveillance/routine/coverage/en/index4.html, accessed 9 March 2015.

and keep them from fulfilling the full promise of immunisation. This, along with the convening of the WHO SAGE Working Group and NVAC committee on these issues, signifies a welcome recognition of the importance of understanding vaccine confidence towards preventing infectious disease and safeguarding public health.

What do we mean by vaccine confidence?

Vaccine confidence, the subject of this report, concerns the belief that vaccination – and by extension the providers and range of private sector and political entities behind it – serves the best health interests of the public and its constituents. The Oxford English Dictionary defines confidence as “the mental attitude of trusting in or relying on a person or thing”. In light of that, we are not examining the well-studied domain of supply and access barriers to vaccination, but rather what is typically called the “demand” side of immunisation. However, our focus on confidence takes the “demand” rubric a step further than the more traditional notion of building demand through increasing knowledge and awareness of vaccines and immunisation to understanding what else drives confidence in vaccines, and the willingness to accept a vaccine, when supply, access and information are available. In other words, understanding vaccine confidence means understanding the more difficult belief-based, emotional, ideological and contextual factors whose influences often live outside an immunisation or even health programme but affect both confidence in and acceptance of vaccines.

Changed publics and technology revolution

Some of the significant contributing drivers to the state of vaccine confidence have included: 1) the dramatic change in the modes and speed of information exchange; 2) the scale of “big data” information collection and analysis; and 3) new on-line mechanisms for virtual “communities” of like-minded people to self-organise around shared beliefs, ideologies and concerns well beyond their local geographies.⁸ Communication today is far more horizontal and less hierarchical, and previously trusted “authorities”, including the scientific and medical community, are challenged by freely available online arsenals of information – from robust scientific evidence to various shades of information and misinformation. These “post-deferential” publics demand dialogue and participation in health policy decisions as well as their own health choices, including decisions about whether or not to accept vaccines for themselves or their children.

Confidence in terms of social layers

Vaccine confidence is a social and psychological phenomenon. Its roots lie within individual members of society, and in their perceptions, words, and actions.

Vaccine confidence is also characterised by the groups and institutions that interact to influence the state of vaccine confidence within populations or societies. This report particularly recognises three groups whose confidence is of collective importance: the public, health providers, and political and policy actors.

Among the public, vaccine confidence comprises confidence in the safety and efficacy of the vaccine, confidence in the competence and motives of health workers providing vaccination, and confidence in the good intentions of the politicians and policy-makers who determine vaccine regulations and schedules. Distrust in, or uncertainty about, any of these actors can undermine demand for vaccines among the general public.

Health providers' and political actors' own confidence in the safety, efficacy and relevance of vaccines is also crucial as it influences the confidence of the publics they serve.

A health worker with low confidence in a particular vaccine will likely project their uncertainty – explicitly or implicitly – to their patients;⁹ a politician or policy-maker with low confidence or reluctance about a vaccine will be more prone to make policy decisions against scientific evidence, if pushed by questioning, highly vocal individuals or groups.¹⁰ Every level of confidence matters.

Vaccine acceptance: the roles of confidence, convenience and complacency

Vaccine uptake can be characterised as the outcome of three key determinants: convenience, complacency, and confidence.¹¹

Convenience relates to the ease of access to vaccines. Are they provided at a location and time that makes it possible for eligible people to access them? Complacency refers to a feeling that vaccines – or a particular vaccine – are not that important, or that there is little risk of the disease that the

vaccine protects against. Confidence has been defined by the SAGE Working Group on Vaccine Hesitancy as "trust in 1) the effectiveness and safety of vaccines; 2) the system that delivers them, including the reliability and competence of the health services and health professionals and 3) the motivations of the policy-makers who decide on the needed vaccines."¹¹ While recognising the interrelatedness of these three determinants, this focus of this report will be primarily on the domain of confidence.

The Vaccine Confidence Project was set up in 2009 to develop a systematic approach to understanding, monitoring, and responding to issues of public trust and confidence in immunisation and immunisation programmes. This report seeks to summarise and synthesise the developments of the past decade, which has been extraordinarily rich with challenges, innovations, and lessons for the advancement of vaccine confidence worldwide.

Public trust matters. When strong, public confidence and trust can help overcome even the most difficult hurdles – maintaining uptake despite uncertainty and bolstering cooperation in times of crisis. Without trust, even the best science and public health strategies can become impotent.

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Chapter 2

Confidence challenges and successes over the past decade

The story of Polio Eradication offers touchstone lessons relevant to diseases as diverse as Tetanus, HPV, and Meningitis

Confidence in vaccines and immunisation programmes is a dynamic and changing phenomenon. This chapter looks at a range of different vaccines and different settings where confidence issues have been overcome. It recognises the importance of ongoing trust-building and sustaining to ensure the success of any immunisation effort.

The polio story

The experience of the Global Polio Eradication Initiative has been an exceptionally rich source of learnings in the realm of confidence, as it has been facing some of the most challenging situations in the very last mile of a multi-decade initiative to end polio. Where some initiatives might have given up when "confronted with mistrust, resentment, fatigue and complacency",¹ polio eradicators persevered.

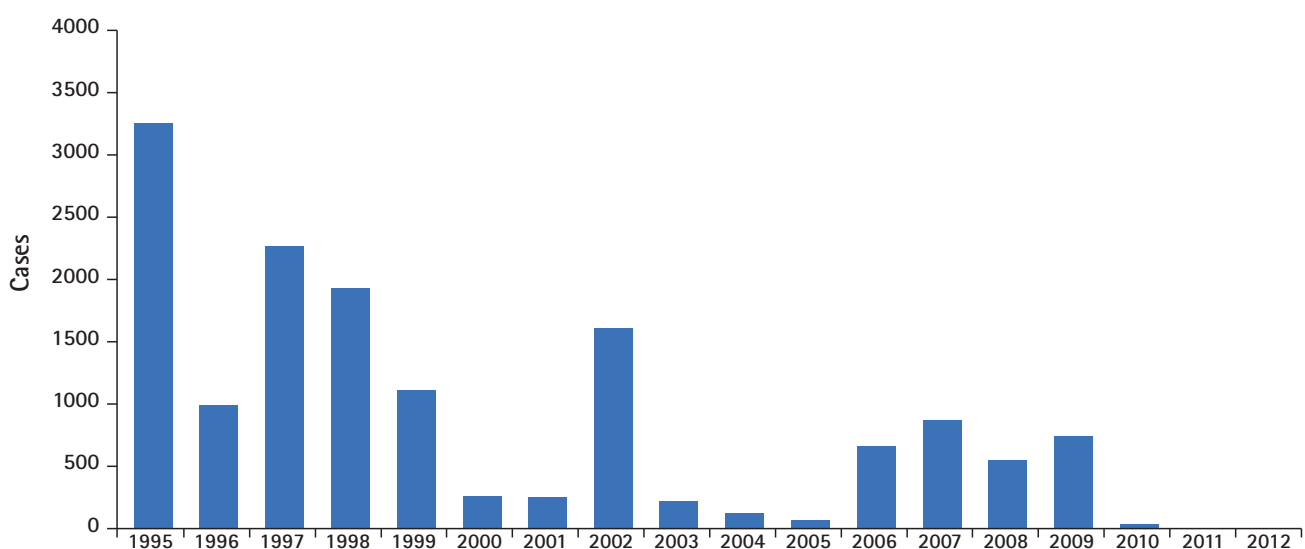
Polio eradicators saw one of their greatest triumphs in January 2014 when India was finally declared polio-free. This success is all the more remarkable given the difficult situation that the polio programme faced in India just over a decade ago, including active community resistance and opposition to polio vaccination in some populations. In 2002, India experienced a resurgence of polio – an estimated 1,600 cases

– which prompted a strengthening of social mobilisation and vaccination delivery strategies to rebuild public confidence and improve coverage. Until 2009 India was home to half of all cases globally, further highlighting the potential power of collective political, provider and public confidence and commitment in turning situations around.

In India's concerted efforts to contribute to meeting the original global polio eradication goal "by the year 2000", the frequency of national immunisation days had been tripled from two to six per year, and supplemented with an additional five sub-national immunisation days. House-to-house vaccination was introduced, where previously campaigns had been carried out at fixed vaccination points. A nationwide publicity campaign was also rolled out, bringing in politicians, Bollywood celebrities, and cricket players to raise the profile of the campaigns – an all-out sprint to the millennium deadline.

Yet even this was not enough. Although it brought polio vaccination coverage (percentage of under-five children receiving at least two doses of oral polio vaccination) from 92.0% in 1998 to 98.6% in 2000,¹ transmission remained uninterrupted, and as the 2000 deadline passed, public energy waned. Meanwhile, families who had previously been content

Figure 1: Poliovirus cases in India 1995-2012



This graph tracks India's journey from suffering the world's greatest burden of polio cases, through to its successful elimination of the virus.

Source: Adapted from John TJ and Vashishtha. 2013. Eradicating poliomyelitis: India's journey from hyper-endemic to polio-free status. Indian Med Res. 137(5), p.881-894. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/23760372> [Accessed 19 March 2015].

to have their children vaccinated twice a year grew weary of the incessant campaigns and, as the years went by, their fatigue turned to resentment: the need for repeated doses was, to laypersons, peculiar and suspicious, and the reasons for the sudden intensification of activity since 1998 remained obscure to many.

This gave way to a flourishing of anti-vaccination rumours, particularly among the underserved, predominantly Muslim, populations of Uttar Pradesh. The most common allegation was that Oral Polio Vaccine (OPV) caused sterility, foreshadowing the rumours that, in 2003, contributed to the litany of reasons for the eleven-month boycott in northern Nigeria. In India, the sterilisation idea gained additional credence from the memory of a coercive sterilisation campaign in the 1970s.² In addition, the persistence of polio cases among partially-immunised children gave rise to perceptions that the vaccine was ineffective in preventing the disease, or worse, that it was the actual cause of polio in the first place.

As rumours proliferated and negative attitudes calcified, some parents began hiding their children when vaccinators arrived. Anonymous provocateurs distributed pamphlets reinforcing the sterilisation rumour, local leaders inflamed tensions to their own profit and, in a few cases, communities collectively refused to admit vaccinators into their villages.

UNICEF conducted research to analyse this new roadblock to eradication, and found that in addition to those who believed the various rumours about OPV, a substantial portion of unvaccinated households were simply unaware of campaign dates, or had become unwilling to take their children to vaccination booths since the recent introduction of house-to-house campaigns. Hence a key component of the communications response was an enhanced media presence

for the programme. However, the marginalised groups most likely to refuse vaccination were also less likely to have access to mass media and a large part of the solution depended on interpersonal communication, supplemented with posters, wall writings, and banners "to create a visual presence".¹

To improve prospects for immunisation in the long run interpersonal outreach was conducted by a network of more than 2,000 social mobilisers, dubbed SMNet (Social Mobilisation Network), whose aim was to build trusting relationships with high-risk communities.

In an additional strategy aimed at mitigating resentment stemming from the lack of health services besides OPV, mobilisers organised day-long Health Camps, which provided other needed health interventions alongside polio vaccination. Social mobilisers also helped track which houses had been immunised, which had refused, and which might or might not have hidden children as a form of "silent refusal". Monitoring data showed meaningful improvements in coverage rates in communities served by the mobilisers.

India's success was not only a confidence-builder and public health success locally, it has been an invaluable confidence-builder for the Global Polio Eradication Initiative.

The northern Nigerian boycott of polio vaccination from 2003-2004

"I don't think you should be overly concerned about whether or not the conspiracies make sense. What you need to explain is why people would come up with those conspiracies in the first instance. Why is the soil consistently fertile? Why do those conspiracies easily find roots in places like Nigeria and Pakistan? Underdevelopment connects places like Pakistan and Nigeria, but the other element is religion. Islam. And it's not just because

DR Congo case study: An anti-vaccination religious leader becomes a quiet advocate

Another key example of religious leader engagement comes from polio eradication in the Democratic Republic of Congo, in the south-eastern province of Katanga. In 2009, UNICEF worked to bring around a staunch opponent of vaccination, Pastor Paul 2, the "Elephant King" of the Kitawala Filadelphie religious movement. The Kitawalas reject what they see as Western ways of life, including medical technologies and the polio vaccine in particular. "I refused because of God," said Pastor Paul 2, nicknamed PP2. "In the Bible, Matthew speaks of King Herod. He had learned that a baby king was born in the country, and he went into the hospital. He went there to kill all children aged 0 to 5 years. Book of Matthew, chapter 1, verse 1-50. At the time we saw polio occur in the hospital, we also saw the polio vaccine coming here for free. The vaccine is also for children from 0 to 5 years. How can we explain this?"²³

As PP2 slowly came around to the possibility of permitting vaccination, he also recognised that he himself would have to convince his followers as well – by no means an easy task. For years, PP2 preached against vaccination, and indeed all things Western, foretelling to his flock how they would ultimately achieve "...victory in the war against Europe in 2015". So, although he recognised the value of the vaccine, his actions were constrained by the expectations of both his own community and those of neighbouring pastors. If he moved too suddenly towards vaccination, either group could throw him out of power, undoing years of work by UNICEF envoys, and making it far less likely that another pastor would prove receptive.²⁴

His short-term solution was to conduct vaccination in the neighbouring villages using "the Owl Approach", that is, under cover of darkness. In one night, over 100 children could be vaccinated by torchlight. PP2 would not permit daylight campaigns for fear that his more conservative neighbours would think he had "yielded". However, a longer-term plan was also put in place: PP2 agreed to send five of his sons to receive free training in hygiene and disease prevention.²⁵

This kind of transformative change is not always an option, and it is especially difficult to engage productively with such deeply-held beliefs as those of the Kitawala movement. When such a leader as PP2 can be identified, engagement like this may be possible.

The example of MenAfriVac: An inspiring success story that built confidence

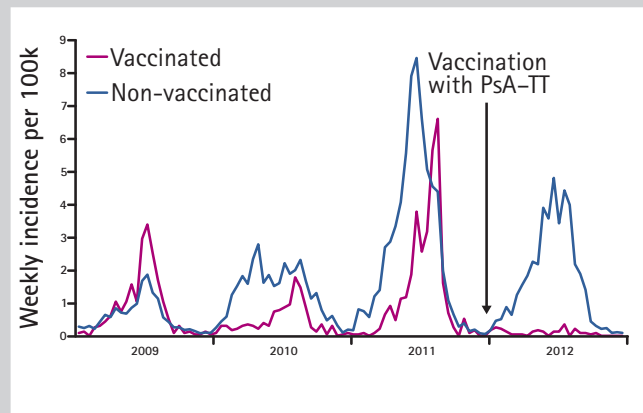
"It's a great Indian success story," said Dr. Jacob John, a former virologist of the Christian Medical College (CMC), Vellore.²⁶

Dr. John was referring to MenAfriVac, a meningitis A vaccine manufactured by the Pune-based Serum Institute of India that has the capability to stay stable at higher temperatures (up to 40° C) than the usual 2–8° C needed. This is particularly important in low-income countries where electricity for refrigeration is less available and vaccine shipments can take hours or days to reach remote locations.

While the MenAfriVac vaccine is a success story for India which produced the vaccine, the even bigger success is the health outcomes in Africa's meningitis belt, where meningitis-related mortality was as high as 75% in some settings. In Chad 1.8 million people under 29-years-old were vaccinated with the new vaccine in December 2011, resulting in a dramatic 94% reduction in meningitis cases in 2012.

The tremendous success of the vaccine was not without its initial challenges. In December 2012, in a settlement in northern Chad, a group of children fell ill after receiving their vaccinations, fuelling a spread of negative media and conspiracy theories both locally and through some international anti-vaccination networks. The campaign was stopped to investigate the cause of the children's illness, which was characterised by an international team as an episode of mass psychogenic illness. However, during the month-long assessment period rumours about the vaccine spread like wildfire.

Figure 2: MenAfriVac impact on meningitis cases



Comparing vaccinated against non-vaccinated populations, this figure illustrates the profound impact of meningococcal conjugate vaccine on disease incidence.

Source: Adapted from: Daugla, D.M. et al., 2014. Effect of a serogroup A meningococcal conjugate vaccine (PsA-TT) on serogroup A meningococcal meningitis and carriage in Chad: a community study [corrected]. *Lancet*, 383(9911), p.40–7. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24035220> [Accessed 19 March 2015].

On January 9, 2013, the Chadian weekly publication *La Voix* reported on adverse events following immunisation with MenAfriVac, indicating cases of vaccinees fainting or experiencing seizures or paralysis.²⁷ *La Voix* is a print-only publication, and its story was not picked up by any major news organisation (although it was colourfully repeated by anti-vaccination groups on the Internet). Later that month, the Minister of Health gave a public statement on the findings of an independent international expert mission that tested the vaccine samples and found no link between the vaccinees' symptoms and their immunisation.²⁷

The affected individuals themselves, ranging from 8 to 25-years-old, were found to be neurologically normal and generally healthy, but experienced acute "crises... triggered by noise, visits by foreigners, and the occurrence of crises among other patients". One child who had not been vaccinated also claimed to have the same symptoms.²⁸

All of this supported the interpretation of the symptoms as a mass psychogenic phenomenon, or "collective hysteria". In the case of MenAfriVac in Chad, no further issues were reported after the investigation was complete. The vaccine was relaunched, supported by a concerted effort of positive messages and trust building.

Muslims are less educated, illiterate, or anything like that. It's because it feeds into the global theme of Muslim victimhood," says African politics professor Ebenezer Obadare.²³

During the northern Nigerian boycott of polio vaccination in 2003–2004, the most obstinate opponent to OPV was Kano State Governor Ibrahim Shekarau, who was the first to halt the polio programme and the last to permit its resumption. He was reportedly motivated to block the central government's eradication agenda out of political opposition to President Olusegun Obasanjo, a Southern Christian who had recently won re-election despite opposition in Kano and other predominantly Muslim regions.⁴ Governor Shekarau's boycott of the polio programme was a jab at the central government from the Muslim periphery, made possible by a popular rumour that OPV was a Western conspiracy to kill or sterilise Muslims. This rumour was particularly fuelled by the Supreme Council for

Sharia in Nigeria (SCSN) and its president, Dr. Datti Ahmed,⁵ who alleged that, "modern-day Hitlers have deliberately adulterated the oral polio vaccines with anti-fertility drugs and contaminated it with certain viruses which are known to cause HIV and AIDS."⁶

Rumours about vaccines causing sterilisation were not new. Other vaccines, such as the tetanus vaccination campaigns, had also struggled with public distrust due to such fears. And, while Nigeria was facing its boycott, India was facing similar rumours about vaccines causing sterilisation, as well as other anxieties, among pockets of refusing and hesitant communities in Uttar Pradesh, India. However this resistance did not coalesce into a state-wide boycott.

In Kano state, the free provision of polio vaccination appeared suspicious to populations that had few health services and were suffering diseases they perceived to be more

Global polio eradication: The precariousness of progress

As 2012 drew to a close, optimism was running high for the Global Polio Eradication Initiative. Polio transmission in India had been interrupted. The three remaining endemic countries (Pakistan, Nigeria, Afghanistan) had made significant programmatic improvements. Some believed that success was imminent; that polio would soon be history.

Within a matter of months, this optimism quickly unwound.

- Targeted killing of polio vaccinators in Pakistan shocked the world and created major operational constraints.
- Polio virus entered Waziristan, a part of Pakistan in which polio vaccination had been – and remains – banned by Taliban commanders.
- The national structure for managing polio eradication in Pakistan was dismantled at a time when it needed to be strengthened.
- Nigeria's security situation deteriorated. Here too, vaccinators tragically lost their lives and the programme's operations were severely impaired.
- Nigeria polio virus was exported to Somalia, where it infected a population unprotected against polio because of an al-Shabab ban on vaccination that remains in place.
- Pakistan polio virus also spread to Syria, causing a major outbreak amidst the country's civil war. Pakistan polio virus also spread to Israel, West Bank and Gaza, and Iraq, and Nigeria polio virus to Cameroon and Equatorial Guinea – each outbreak over-stretching the global programme's resources and credibility.
- In 2012, there were 223 polio cases in five countries. In 2013, there were 407 cases in eight countries.

*Report of the Independent Monitoring Board of the
Global Polio Eradication Initiative – May 2014*

serious than polio. Moreover, wars in Iraq and Afghanistan had heightened perceptions that the West was at war with Muslims. Additionally, the memory of child deaths in Kano State suspected to be connected to Pfizer's trials of an anti-meningitis drug, Trovan, heightened the plausibility of claims that Western medicines were killing children.

Confidence building

The Global Polio Eradication Initiative secured a direct conduit for political persuasion in the person of Ibrahim Gambari, UN senior advisor for African affairs. As the child of a northern Muslim father and a southern mother, Gambari was a political bridge, yet he still struggled to convince Governor Shekarau, and asked him, "suppose you are wrong... You are going to condemn a whole people to this life of misery. At least consider you may be wrong."⁷ Gambari opened the dialogue, and he conveyed the cost that a continued boycott would bring to Shekarau's reputation.

In another effort to build trust and restart the campaign, UNICEF drew attention to the fact that the polio vaccine was being procured from an Indonesian producer, allowing Shekarau to save face by reporting that the vaccine was sourced from a Muslim country.⁷ The Indonesian manufacturer also helped by opening its facilities for inspection by Nigerian delegations.

Vaccination in Kano finally resumed in July 2004, but substantial damage had already been done. It has taken another decade to rebuild trust and achieve the current progress towards polio eradication.

Importance of vigilance and continuous trust building

Even after the high-level political issue was resolved, distrust and opposition remained widespread among religious leaders and the general public.⁸ Greater attention was then paid to local communities, spurring new engagement with religious and traditional leaders, and a greater emphasis on listening to communities' felt needs.

In hindsight, the programme may have missed crucial opportunities to engage the Nigerian public and manage the spread of misinformation, but instead "[t]he health community responded to the rampant rumours with medical responses, seeking to clarify the science or 'explain away' the rumours."⁹

A new focus on interpersonal communication in social mobilisation emerged in Nigeria, as a route to changing social norms around vaccination, not unlike the approaches that were successfully used in India. Social mobilisers had previously concentrated on announcing the dates and locations of upcoming immunisation activities in each community. The new strategy aimed to engage local opinion leaders and organisations with influence in their communities. These included "traditional leaders, women's networks, religious associations, community health volunteers, and field workers. Extensive training was conducted to familiarise opinion leaders with the goals of the Polio Eradication Initiative, strategies, and basic epidemiological information."⁸

The polio programme also made particular efforts to secure support from key national figures such as the Emir of Kano and the Sultan of Sokoto, and in August 2005 inaugurated a Nigerian Forum of Religious and Traditional Leaders and the Media on Immunisation and Child Survival to advance this engagement. More broadly, the new social mobilisation strategy included outreach to local leaders to support the programme, for example by publicly administering polio vaccination to their own children, and by voicing support in sermons and other public statements.¹⁰

These engagement activities helped draw out the importance of responding to communities' felt needs for health services apart from polio. In high-risk areas in the North, vaccination posts also offered soap, pain killers, oral rehydration salts, deworming medicines and insecticide-treated bednets.¹¹ "Immunisation plus days," were introduced with polio vaccination administered alongside a bundle of health interventions such as other vaccines (measles, DPT, tetanus toxoid) and vitamin A supplements.

A review of Nigerian polio communications¹² found

Tetanus toxoid and the Catholic Church: The persistence of a rumour over two decades

In October 2014, concerns about the tetanus vaccination programme appeared in a statement issued by the Catholic Health Commission of Kenya/Kenya Conference of Catholic Bishops.²⁹ The concerns were initially more focused on the sense of exclusion felt by the church, and the perceived lack of transparency with the public, leading to suspicions about the vaccine and the campaign. The statement listed three key issues:

- There has not been adequate stakeholder engagement for consultation. This is despite previous promises by the Ministry of Health to be engaged as a key stakeholder.
- There has been limited public awareness unlike other related campaigns such as polio vaccination.
- There has been limited public information on the rationale with a background that has informed the initiative since we raised an issue in March 2014.

The Kenya bishops also raised four specific questions:

- Is there a tetanus crisis in Kenya? If this is so, why has it not been declared?
- Why does the campaign target women of 14–49 years?
- Why has the campaign left out young girls, boys and men even if they are all prone to tetanus?
- In the midst of so many life-threatening diseases in Kenya, why has tetanus been prioritised?

And, in the same statement, they revived a 20-year-old rumour that the vaccine contained sterilising agents.

"We are not convinced that the government has taken adequate responsibility to ensure that Tetanus Toxoid vaccine (TT) laced with beta human chorionic gonadotropin (b-HCG) sub unit is not being used by the sponsoring development partners. This has previously been used by the same partners in Philippines, Nicaragua and Mexico to vaccinate women against future pregnancy..."²⁹

In 1994, allegations were raised by a global network of Catholic Pro-Life groups that the tetanus vaccine contained sterilising elements. The rumours' germ came from a published study³⁰ about a contraceptive vaccine which mentioned tetanus toxoid as a protein carrier, unrelated to the tetanus vaccine. The rumours spread from the Philippines to Mexico, and thence to Bolivia and Nicaragua.³¹

WHO sent the vaccine for testing at independent laboratories, all of which produced negative or non-significant results.³² An epidemiological study published the following year found no association between tetanus vaccination and spontaneous abortion in the Philippines.³³ Nonetheless, the reports had a significant negative impact on tetanus vaccination uptake, following a court injunction filed by a coalition of Catholic organisations which led to a drop of 45% in the Philippines. With the help of Cardinal Miguel Obando y Brava, its administration was halted in Nicaragua as well, and in Mexico, Pro-Life groups managed to gain the support of several national legislators in charging the Secretary of Health with genocide.³¹

Ultimately, PAHO and WHO engaged the Catholic church directly. WHO suggested further testing be carried out at a facility of the Vatican's choice. The Hospital Gemelli in Rome

was chosen and conducted new tests with negative results, rebuilding the church's confidence, at least for a while.³⁴

The availability of decades-old tetanus misinformation on the internet may have helped build this recent case against the tetanus vaccine. Anxieties about secret sterilisation schemes are not uncommon in immunisation programmes, particularly those which are mass campaigns. One publication³⁵ identified 32 examples of sterility rumours surrounding vaccinations and (to a lesser extent) other health interventions, within the African continent alone.

One decade after the 1990s tetanus anxieties, the issues reappeared – this time in a memorandum issued in northern Nigeria outlining the rationale for boycotting the polio vaccination campaign. The reference to tetanus vaccination sterilisation suspicions, were among reports of population control policies issued by the USA, and suspected links between the polio vaccine and AIDS and mad cow disease.

As in the Kenya Bishops statement, the Nigerian Islamic Council raised questions such as: "Has polio assumed epidemic dimension in Nigeria, especially in the North?", "Why should polio (a lesser disease) attract massive funding and continuous inoculation?", "What about malaria and measles? Are they not more deadly than polio?" and "Is the Polio Eradication Programme another plot to facilitate population control among Muslims?"³⁶

Religious organisations can be powerful agents behind the spread of vaccine concerns, through their national and international networks. However, these networks can alternatively be valuable partners in addressing issues of concern and building confidence, as trusted information brokers. It is crucial to engage key religious stakeholders as early as possible to obtain their buy-in and ensure they do not feel excluded, and that their felt needs are heard.

Table 1: Coverage for tetanus toxoid in the Philippines 1987-1996

Year	TT2+ coverage
1987	28.9%
1988	37.2%
1989	43.6%
1990	42.3%
1991	53.7%
1992	16.8%*
1993	70.0%
1994	69.3%
1995	57.5%
1996	47.0%

* Incomplete reporting.

Source: UNICEF Kenya. 2001. *Combating Antivaccination Rumours: Lessons Learned from Case Studies in East Africa*. Nairobi. <<http://www.path.org/vaccineresources/details.php?i=144>> [Accessed 9 Jan 2015]

decreases in the numbers of missed children between November 2006 and March 2007 in key Northern states, as well as country-wide improvements in the immunisation status of wild polio cases, although the authors stressed that higher-quality data were needed to evaluate these impacts.

The Independent Monitoring Board (IMB) of the Global Polio Eradication Initiative

The IMB has played a vital role in critiquing and guiding the Global Polio Eradication Initiative. As an independent body of experts, the IMB interacts regularly with the key GPEI partners and reviews the critical issues facing individual countries as well as the overall global initiative.

The reports of the IMB are candid – sometimes uncomfortably so, not beholden to either national or international political correctness, but beholden to the eventual success of global polio eradication. The IMB serves as a provocateur, and yet brings a refreshing pragmatism:

"The Programme must open its ears fully to understand what is top – the unique needs of every community – and respond to these needs. A community furious at the amount of rubbish on their streets? Send in sanitation lorries with the polio vaccination teams. A village with no clean water? Offer chlorine as well as polio vaccine. A slum suffering an outbreak of infant diarrhoea? Polio social mobilisers provide oral rehydration solution."¹³

In 2013, when Nigerian academics began distributing anti-vaccination CDs, the Global Polio Eradication Initiative's Independent Monitoring Board (IMB) asked:

"How extensive, and how deeply ingrained, are anti-Programme sentiments in northern Nigeria? The Programme does not appear to know; it is flying blind. Perhaps there is just low-level resistance to the idea of polio vaccination. But perhaps there is much more serious anti-Programme sentiment bubbling away under the surface, ready to explode. Several well-informed IMB sources fear the latter to be closer to the truth, but there are few data available to really tell us. The Programme needs to know which of these situations it is in."¹⁴

The IMB serves as a model for other immunisation and public health initiatives, one that does not allow overconfidence which is sometimes as much a liability to progress as is underconfidence.

A decade later, new resistance

While all eyes were on the northern Nigerian boycott in 2003–2004, and the equally challenging – but less advertised – pockets of resistance in India, the polio programme in Pakistan seemed to be going well.

However, a decade after the Nigeria boycott the polio eradication initiative faced other challenges of community resistance. Another ban, this time in Pakistan, was put in place in 2012 by militants in the Federally Administered Tribal Areas (FATA). The actors driving this ban claimed they would not allow polio vaccination until the US ceased its campaign of drone attacks against targets in North Waziristan. The announcement of the ban provides a useful insight into the militants' perspective:

15/06/2012

"In the name of Allah!

*Shura of Mujahideen's Administrator Hafiz Gul Bahadur has taken this decision in consultation with his shura that unless the series of drone attacks are stopped, there will be a ban on the administration of polio drops. Because what is the use of the well wishes of such a well-wisher who on one hand, spends billions on the administration of drops for the protection against Polio disease, and Polio happens to one in hundred thousand, on the other hand the same well-wisher (USA) with the help from his servant (Pakistan) is conducting relentless drone attacks due to which hundreds of innocent Waziristanis which include women, children and old people have been martyred. And because of the continuous drone flights almost every Waziristani is either suffering or soon will be suffering from mental disease which is a more dangerous situation than Polio. Also in the Polio campaigns there are strong chances of spying over the Mujahideen by the US and an example of which is Dr. Shakil Afridi. So from today onwards a ban on the administration of polio drops is announced."*¹⁵

GPEI had been facing violent opposition from militant groups in Pakistan since 2012, including attacks on polio vaccination teams and their guards in a campaign of targeted violence. Although the attacks unsettled the confidence of health workers participating in the vaccination campaigns, most continued with remarkable courage and commitment.

Mullah Fazlullah, a major militant leader in Pakistan, had denounced and threatened the lady health workers (LHWs) who deliver polio vaccination, on the basis of the perceived impropriety of female employment and unaccompanied public movement. At the same time, Fazlullah promulgated the same sterilisation conspiracy theories that had been circulated in India and Nigeria, while accusing vaccinators of being servants of America.¹⁶ There was no single cause driving the resistance and violence, and no single strategy that could address the challenges to the polio programme.

This was not the first time that the GPEI had encountered violence. Eradicators had successfully carried out vaccination campaigns in diverse conflicts by organising one-day truces or "days of tranquillity" in, for example, El Salvador, Sri Lanka, Afghanistan, Sudan, and DR Congo.^{17, 18} However, polio workers had never been specifically singled out for attacks as they were in Pakistan.

In addition to the challenging violence and vaccine ban, some communities resisted vaccination as a bargaining chip to demand other services or public works. Some villages refused to admit polio vaccination teams until a road was repaired, electricity was provided, or demanded that the polio vaccines be given together with other needed services.¹⁹ This type of stoppage was not about the quality or safety of the vaccine itself, but an attempt to capitalise on the high visibility of the polio campaign and the eradication goals, to leverage other felt needs.

The GPEI has taken a multi-pronged approach to addressing these issues in Pakistan, partly informed by its prior experiences in India and Nigeria, but recognising the distinct local dynamics in Pakistan. Global networks of influence were mobilised to

apply international pressure on the Pakistani government to find a solution to the targeted violence towards polio workers and the Waziristan ban, including direct engagement from the World Health Organization Director-General and key donor governments such as China and the UAE.²⁰ The Global Polio Eradication Initiative also worked with Islamic leaders from Saudi Arabia, Egypt and Qatar to counter religious narratives against polio vaccination, and produced a book²¹ of pro-vaccination fatwas, which is now carried by vaccinators. Finally, new approaches for vaccination campaigns have been developed that embed polio vaccination within a broader package of health services. The *Sehat ka Insaf* (Justice for Health) model, used in Peshawar, includes vitamin A supplements, hygiene supplies and a number of additional vaccines offered alongside polio vaccination.²² This is part of a broader effort to be responsive to the needs of communities that have priorities apart from polio eradication. Overall a mix of community level engagement along with political strategies to address external security risks to the programme will continue to be needed until the last case of polio is eliminated.

This chapter has reviewed vaccine confidence issues, using these stories as a window into the challenges and innovative responses. The story thus far showcases the global health community's resilience, adaptability, and perseverance in the face of these challenges. India is now declared polio-free. Nigeria, the site of the most damaging vaccine boycott in history, is well on its way to elimination as well. This progress is due in large part to public engagement efforts on an unprecedented scale, made possible through a marriage of social research and mobilisation designed to meet the felt needs of the public, but also to support the vaccine providers, whose confidence has also been sometimes shaken by both external events as well as resistant publics.

Despite the vaccine confidence challenges, experience teaches that good listening and sincere engagement can bring about impressive progress, and even win over entrenched opponents such as Pastor Paul 2 in DR Congo, and the governor of Kano, Nigeria, who went from leading the charge against polio vaccination to administering OPV drops to his own children on a public stage. As effective as some of these confidence-building strategies have been, one important lesson is that most of them could have been mitigated with earlier engagement. The next chapter explores new approaches to monitoring vaccine confidence to detect early signals of concerns that – if listened to – can be valuable cues to prompt early engagement and prevent confidence crises and their risks to immunisation programmes.

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Chapter 3

Measuring vaccine confidence: No single metric tells the story

Interdisciplinary research, and both “fast” and “slow” data sources, are key to understanding vaccine confidence

Vaccine confidence is dynamic and must be carefully examined over time. The number of social, cultural and political factors that influence vaccine uptake is also dynamic and evolves over time. While maternal education, for example, has historically been a prime social determinant of vaccine uptake, even this is changing in some contexts. A number of new vaccines and combinations of vaccines are also being introduced globally, and each new product prompts the usual questions of safety, efficacy and relevance that need to be addressed early to build and sustain confidence – Do we need this vaccine? Can we afford it? Does it work? Is it safe?

In addition to these more commonly raised questions are a number of other issues such as religious or philosophical beliefs about health and disease prevention, trust in the health provider, confidence in the health services, trust in the government, and other less tangible, but influential determinants of confidence in and acceptance of vaccination.

The Global Vaccine Action Plan (GVAP) endorsed by the World Health Organization recognises the importance of understanding vaccine confidence as a critical measure of the public's understanding of and demand for immunisation. The Global Plan calls for measuring the “percentage of countries

that have assessed confidence in vaccination at subnational level” as well as capturing the “percentage of un- and under-vaccinated in whom lack of confidence was a factor that influenced their decision.”

Measuring vaccine confidence serves two main purposes: 1) understanding the nature and scale of waning confidence to inform appropriate interventions; and 2) monitoring changes in vaccine confidence to detect and investigate drops in confidence early. Since drops in confidence can be prompted by contextual factors that go beyond the characteristics of the vaccine or vaccination programme as discussed in the previous chapter, measurement tools must also be sensitive to deeper historical, cultural, and political dynamics, not merely more volatile shifts in public opinion.

Using diverse types of data and combining different measurement approaches can produce rich and actionable information in a timely manner, both for “now-casting” the present as well as forecasting future vulnerabilities and identifying opportunities for confidence-building. Changing dynamics of confidence over time can be partly captured through “fast data” gleaned through analyses of social media and on-line searches, while point-in-time surveys can provide

Bringing together fast and slow data to understand the vaccine confidence phenomenon

This figure illustrates the various measurement approaches available to researchers investigating vaccine confidence, and the ways different data sources can be used to understand the phenomenon of vaccine confidence. Surveys and media tracking can provide “fast data”, near-real-time estimates of public perceptions of vaccines, which can be analysed to best understand how to engage the public.

Qualitative and epidemiological research, meanwhile, offer “slow data”, which takes longer to collect, but can provide deeper insights into the predictors of vaccine hesitancy, the social phenomena that can help or hinder vaccination campaigns, and, in particular, long-term contextual factors that create “fertile ground” for a crisis of confidence. Both fast and slow data can also help identify “prompters”, or the factors that can prompt a crisis of confidence, especially when “fertile ground” conditions are present.

Finally, systematic reviews can help synthesise findings from multiple studies across different disciplines, providing researchers and policy-makers with practical wisdom and further issues to study in vaccine confidence.

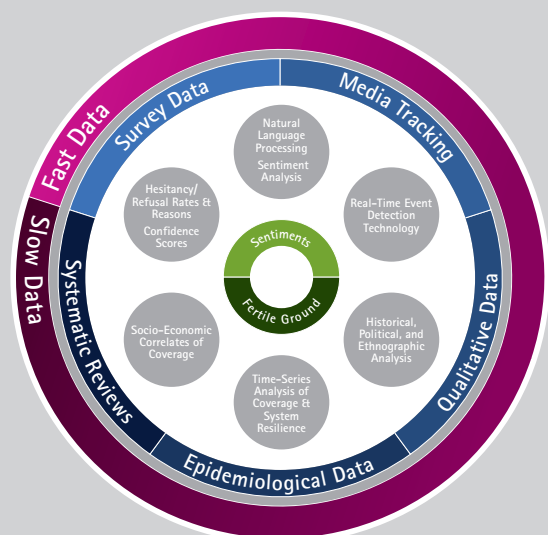


Figure 1: Fast and slow data monitoring cycle

Source: Vaccine Confidence Project. 2015. *The State of Vaccine Confidence 2015*

other important insights into public sentiment, and have the added value of collecting more background information on the populations being surveyed than media monitoring can provide.

Contextual information ("slow data") adds another important layer of both historical and contemporary understanding, bringing socio-cultural and political influences into the analysis of what may be driving public sentiments.

Different measurement tools can tap into different points of the evolution of individual and public confidence. In addition to the methods themselves, the important difference is the time frame they address:

- Specially-designed surveys can measure vaccine confidence at a specific point in time.
- New and emerging media monitoring technologies can flag early signs of waning public confidence or, even earlier, detect potential prompters that can disrupt confidence in real time, as well as monitor changes in sentiment over time.
- In-depth qualitative research can provide insights into complex contextual and historical factors that are slow to change, but influence confidence.

Other indicators which can flag rises and falls in public confidence are changes in vaccine coverage or increases or decreases in the instances of delayed vaccination, although these indicators may be driven by other reasons besides confidence, such as supply-related issues or lack of information. But when access and information are ruled out as the cause of a decline in vaccine coverage or increased delays, confidence is an important area to investigate.

The Vaccine Confidence Index

We introduce a Vaccine Confidence Index that places a finger on the pulse of a set of public confidence sentiments, which influence vaccination behaviours. The closest analogue to the VCI is the Consumer Confidence Index (CCI), which measures consumer confidence, defined as the prevailing degree of optimism about the state of the economy. Like the CCI, the VCI can provide insights for policy-makers, immunisation managers and health professionals. In a sense, the VCI turns

the "public understanding of science" mantra upside down and aims to help medical scientists, health policy-makers and other health professionals understand the public.

This report marks a new collaboration between the Vaccine Confidence Project and Gallup International, through which a set of survey questions to characterise vaccine confidence – a Vaccine Confidence Index – is being rolled out globally. Here we present the results of the first five countries⁴ surveyed to measure confidence in health and immunisation services and how this relates to confidence in and acceptance of vaccines, contributing to a larger global mapping of vaccine confidence.

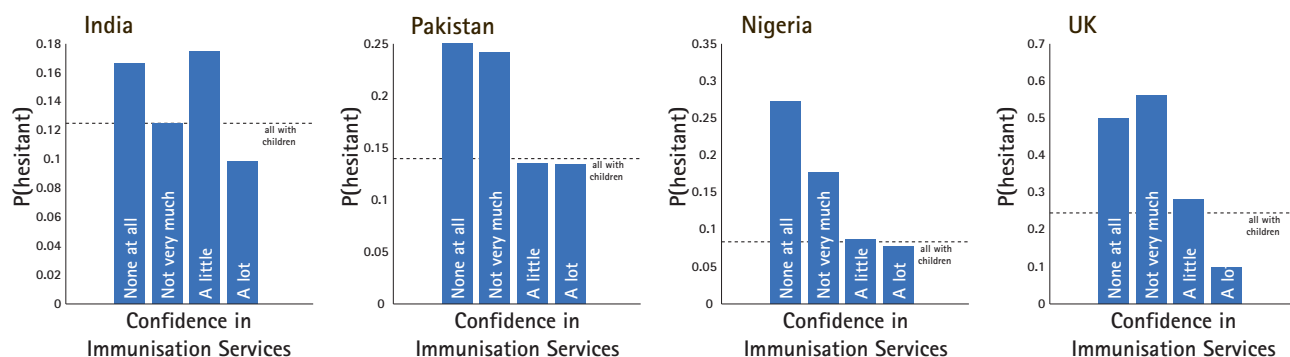
Data were collected against a core set of confidence questions through local-language interviewing of respondents in Georgia, India, Nigeria, Pakistan, and the UK. We examined confidence in immunisation programmes as compared to confidence in other government health services, the relationships between vaccination opinions, reasons for vaccine hesitancy, ultimate vaccination decisions, and their variation based on country contexts and demographic factors. Particularly rich data are now available, through this survey effort, for five states of northern Nigeria.

When the probability of hesitancy was broken down by reported confidence level in immunisation services, most countries exhibited a general dose-response relationship, whereby lower confidence in immunisation services was linked to higher levels of hesitancy. This reinforces other research which points to the importance of the supportive health services for public confidence and acceptance of vaccines.

If, as these data suggest, this survey tool can detect confidence sentiments that are predictive of vaccine hesitancy and, implicitly, vaccine uptake, the next question is, "how much confidence is enough?"

The surveys in each country identified respondents with children under five years of age and asked if these respondents had ever hesitated to vaccinate their children, and if so, whether they went on to accept or ultimately refuse vaccination (note that in Georgia, respondents were asked if they had children under 15 years of age, rather than five).

Figure 2: Relationship between hesitancy and confidence in immunisation services



These graphs show probability of having hesitated to vaccinate in the past, depending on expressed level of confidence in immunisation programmes, in each country for which the requisite data are available. Dotted lines indicate average hesitancy rate for RCU5s, irrespective of confidence in immunisation programmes.

Source: Larson, H., Schulz, W., Tucker, J., & Smith, D. 2015. Measuring Vaccine Confidence: Introducing a Global Vaccine Confidence Index. PLoS Currents Outbreaks. 25 Feb. Edition 1. doi: 10.1371/currents.outbreaks.ce0f6177bc97332602a8e3fe7d7f7cc4.

There is no clear watershed confidence level that is consistent across every country – in India and the UK, hesitancy rises sharply between “a lot” and “a little” confidence, whereas in Pakistan and Nigeria the distinction between “a little” and “not very much” appears to have more impact on behaviour. Linguistic differences between these countries may result in different meanings of “a little” and “not very much”.

Most respondents with children under five had never hesitated to vaccinate, but hesitancy rates varied considerably between countries, with the UK showing the highest rate.

Refusal rates among those who hesitated varied even more, with the highest percentage of hesitants going on to refuse a vaccine at country level being in Georgia (60%) and, at a state level, in Nigeria's Kano state (74.2%) (Table 1).

Results from Nigeria which focus on Enugu, Jigawa, Kaduna, Kano, and Lagos states (Table 2) show that it is still possible to see the effects of the 2003–2004 polio vaccination boycott in Kano state, ten years on. In Kano state, where the boycott lasted longest, hesitancy rates are not exceptionally high but, unlike in other states, the percentage of hesitants who went on to refuse vaccination (74.2%) was the highest of all states. These preliminary findings indicate some variation in “obstinacy” (tendency of hesitants to ultimately refuse), particularly evident in Kano and Enugu states.

Qualitative research (‘slow data’)

Qualitative research is essential to understanding the drivers of changing vaccine confidence, although it is often time- and labour-intensive. Understanding the reasons behind drops or gains in confidence is key to informing the design of interventions – whether to build on successes in building confidence or to address drops in confidence.

Qualitative analysis of vaccine confidence can bring into focus the relevant historical, cultural, and political factors that shape the perception of vaccines, medicine, public health, and government in general within a given population. In the case of the northern Nigerian boycott, for example, Obadare's analysis¹ was that the problem was embedded in marginalisation and deep historical distrust of health authorities and of the West, but was elevated to its notoriously destructive scale by local political interests. These underlying factors were largely unrelated to vaccination itself, but nonetheless made for fertile ground for a public health crisis.

Other survey tools and learnings

In terms of global efforts to map and understand vaccine confidence issues in low and middle-income countries (LMIC), the Global Polio Eradication Initiative has been a leader in the development of surveys on reasons for vaccine hesitancy and refusal. This became an increasing issue as the eradication effort became increasingly close to achieving its goal and faced the last, most difficult remaining pockets of polio of the world.²

Specially-targeted “knowledge, attitude and practice” (KAP) studies have been used to identify vaccine hesitancy issues in particularly high-risk areas where a challenge has been recognised. One study in Karachi, Pakistan, combined a structured questionnaire administered to 1,017 respondents across the city with in-depth interviews conducted with 30 parents in a high-risk Pashtun community – a minority of the Karachi population, yet accounting for 90% of polio cases.³ The most common reason (76.7%) for non-vaccination among low-income Pashtuns was that a family elder or husband did not allow vaccination. Among the middle-high income group, the most common (71.8%) reason for vaccine refusal was due to

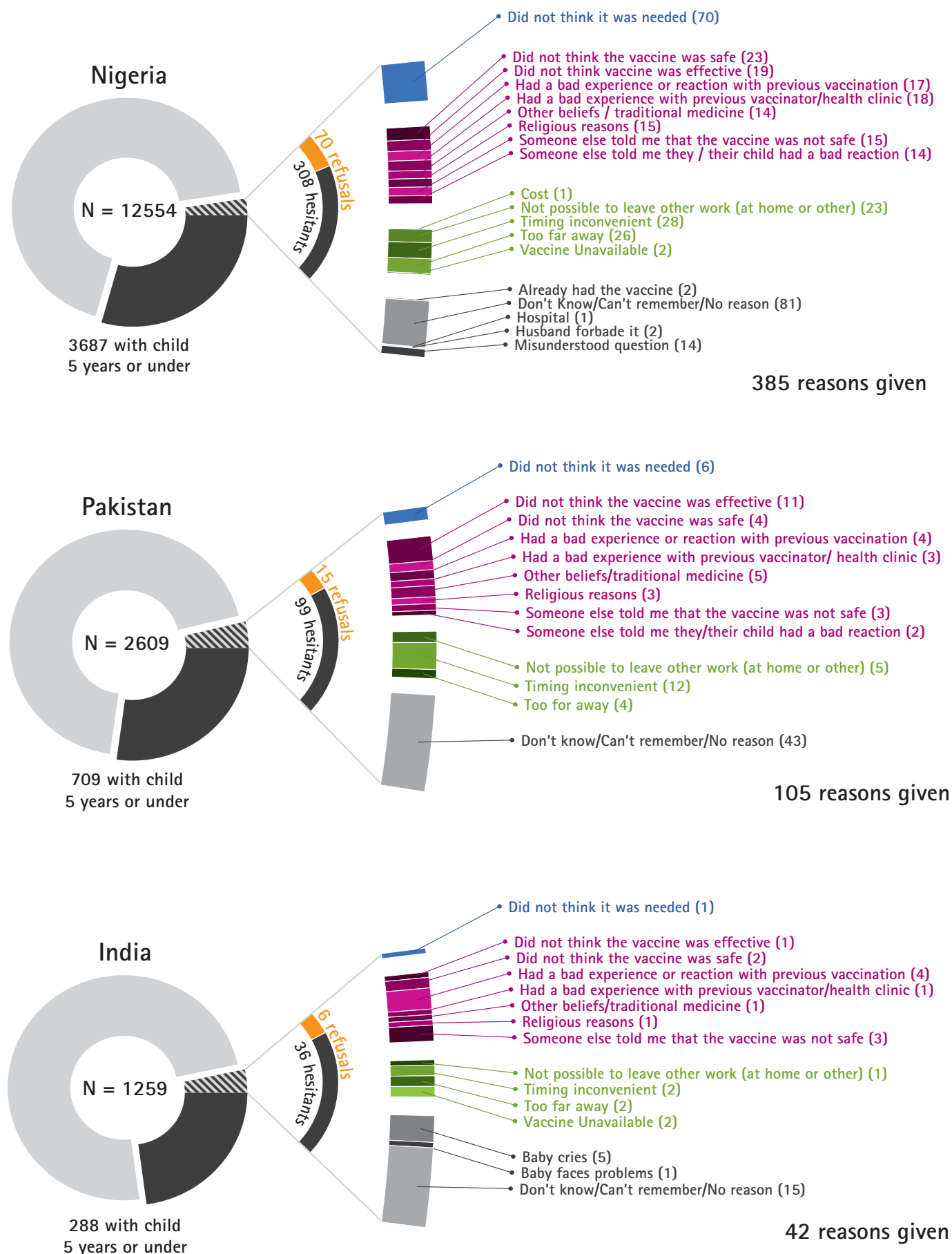
Table 1: Survey size and prevalence of hesitancy and refusal

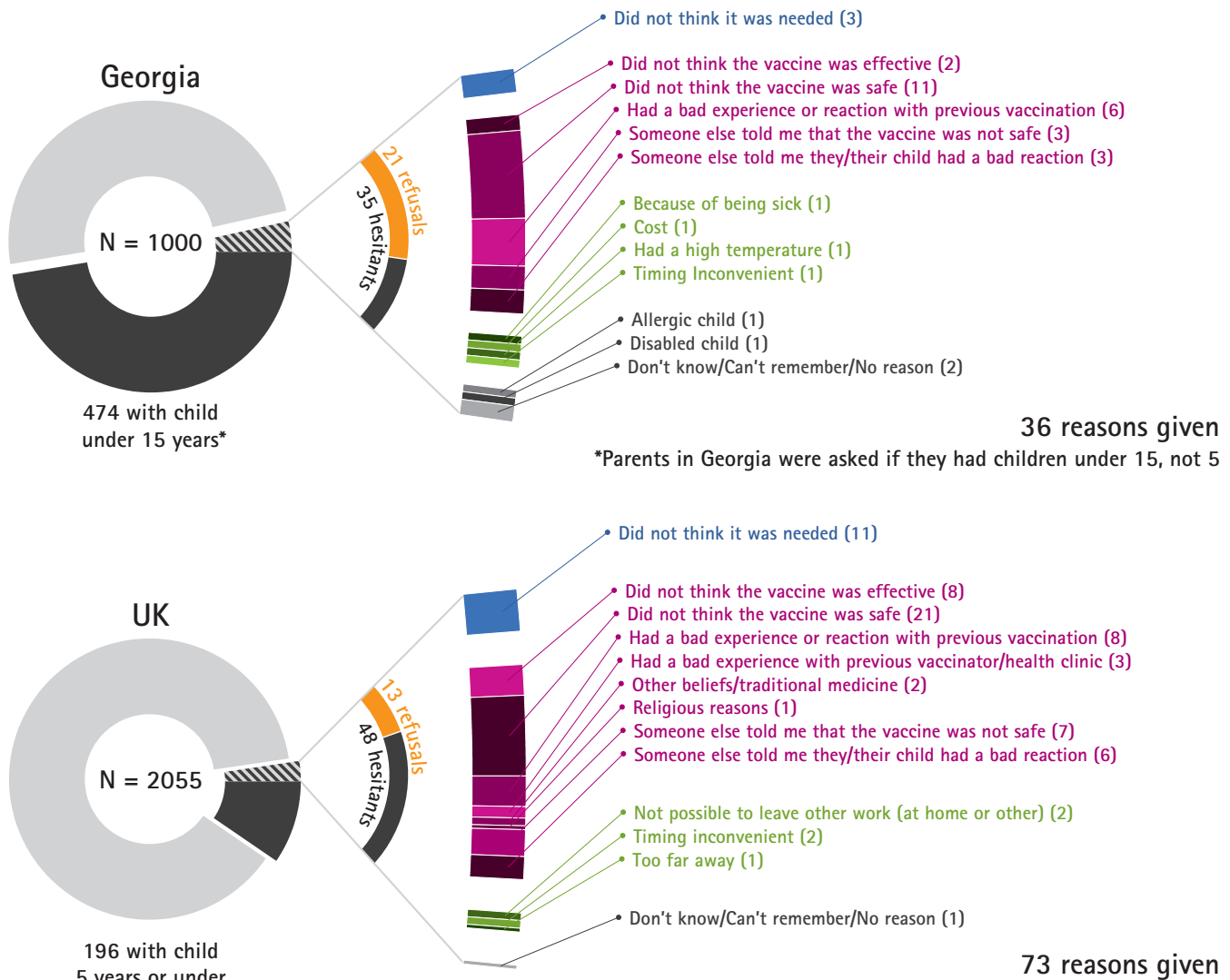
	Survey Size	With Child ≤5 years old (RCU5)	Hesitants	Hesitants as % of respondents	Outright refusers	Outright refusers as % of hesitants	Nigerian States	Outright refusers as % of hesitants
India	1259	288	36	12.5%	6	16.7%	Enugu	29.6%
Pakistan	2609	709	99	13.9%	15	15.2%	Jigawa	9.9%
UK	2055	196	48	24.5%	13	27.1%	Kaduna	16.7%
Nigeria	12554	3687	308	8.4%	70	22.7%	Kano	74.2%
Georgia	1000	474*	35	7.4%	21	60%	Lagos	22.2%
							Total	22.7%

Vaccination hesitancy and refusal are presented in absolute numbers and as proportions. Hesitancy is presented as a proportion of respondents with children equal to or under five, except for Georgia (*) which represents children under 15 years of age. Refusal is presented as a proportion of those who hesitated.

Source: Larson, H., Schulz, W., Tucker, J., & Smith, D. 2015. Measuring Vaccine Confidence: Introducing a Global Vaccine Confidence Index. *PLoS Currents Outbreaks*. 25 Feb. Edition 1. doi: 10.1371/currents.outbreaks.ce0f6177bc97332602a8e3fe7d7f7cc4.

Figure 3: Vaccine-hesitant parents and their reasons





Source: Larson, H., Schulz, W., Tucker, J., & Smith, D. 2015. *Measuring Vaccine Confidence: Introducing a Global Vaccine Confidence Index*. PLoS Currents Outbreaks. 25 Feb. Edition 1. doi: 10.1371/currents.outbreaks.ce0f6177bc97332602a8e3fe7d7f7cc4

Commentary and key to Figure 3

These graphs illustrate the total sample size (whole circle, N=sample size), highlighting the subset of respondents who were parents of children under 5 (dark grey slice), and, further, the subset of parents who reported ever hesitating to vaccinate their children (striped section of dark grey slice). These hesitant parents are further disaggregated by the reasons given for hesitating, classified as:

- Complacency:** Parents who hesitated to vaccinate their child because they felt vaccination was not important, or that the disease prevented by a given vaccine was not severe enough to warrant vaccination.
- Confidence:** Parents who hesitated due to a lack of trust in the individuals or institutions promoting vaccination, doubts about the safety or efficacy of vaccines, or preference for alternative or traditional forms of medicine.
- Convenience:** Parents who hesitated because it was too difficult, costly, or time-consuming to access vaccination services, which can occur when clinics are placed far from a community, or when immunisation campaigns occur at inconvenient times.
- Other:** This category includes parents who could not remember or did not wish to say why they hesitated to vaccinate their child, or gave responses that did not fit clearly into the other classifications.

Table 2: Nigeria state-level analysis of prevalence of hesitancy and refusal

State	With child <5 years	Hesitants	Hesitants as % of child <5 yrs	Refusers	Refusers as % of hesitants
Enugu	841	44	5.23%	13	29.55%
Jigawa	637	101	15.86%	10	9.90%
Kaduna	701	96	13.69%	16	16.67%
Kano	604	31	5.13%	23	74.19%
Lagos	904	36	3.98%	8	22.22%
Total	3687	308	8.35%	70	22.73%

Hesitancy is given in absolute numbers and as a proportion of respondents with children under five years of age. Refusal is given in absolute numbers and as a proportion of hesitants.

Source: Larson, H., Schulz, W., Tucker, J., & Smith, D. 2015. *Measuring Vaccine Confidence: Introducing a Global Vaccine Confidence Index*. PLoS Currents Outbreaks. 25 Feb. Edition 1. doi: 10.1371/currents.outbreaks.ce0f6177bc97332602a8e3fe7d7f7cc4.

Table 3: Reasons for hesitancy categorised by Confidence-Convenience-Complacency

	Confidence	Convenience	Complacency	Other/DK/NR
Georgia	69%	6%	8%	17%
India	49%	18%	3%	31%
Nigeria	36%	20%	18%	26%
Pakistan	33%	20%	6%	41%
United Kingdom	79%	6%	13%	1%

Reasons for hesitancy were classified using the categories of confidence, convenience, and complacency. Responses that did not fit into this classification (predominantly those indicating "Don't Know/Can't Remember/No Reason") were left as "Other".

Source: Larson, H., Schulz, W., Tucker, J., & Smith, D. 2015. *Measuring Vaccine Confidence: Introducing a Global Vaccine Confidence Index*. PLoS Currents Outbreaks. 25 Feb. Edition 1. doi: 10.1371/currents.outbreaks.ce0f6177bc97332602a8e3fe7d7f7cc4.

lack of confidence in the vaccine's safety.

In-depth interviews in the Karachi study were also enlightening: most interviewees believed that the polio vaccine would cause their children to become infertile, and some explicitly claimed that the vaccination campaigns were part of a Western conspiracy against Muslims and Muslim nations such as Pakistan – a similar rumour to the one that contributed to the northern Nigeria polio boycott a decade ago. One-third of parents interviewed did not have confidence that the vaccine was effective at preventing polio, with at least one respondent citing his "evidence" that a friend had contracted polio despite being vaccinated. The government's seemingly excessive focus on polio vaccination was also a major cause of suspicion and distrust, as other health issues were not felt to be given the same priority. Rumours that the vaccine was not halal (i.e. following Muslim dietary guidelines) were also mentioned, though parents said they would be receptive to evidence supporting the vaccine's conformity to halal requirements.³

SAGE survey tools

In the context of their overall work on vaccine hesitancy, the Strategic Advisory Group of Experts (SAGE) on Immunization endorsed a set of proposed survey questions for countries to assess their scale and nature of vaccine hesitancy. The wider selection of vaccine hesitancy survey questions

included a number of confidence-related questions ranging from confidence in the reliability and trustworthiness of the information from official sources, loss of confidence due to negative media, a loss or gain in confidence related to previous experiences with an immunisation or with the health services, confidence related to perception of the effectiveness of vaccines or a particular vaccine, and confidence in the safety of the vaccine. Questions on religious or philosophical reasons for vaccine hesitancy or refusal were less likely to capture specific vaccine-confidence issues, but about another more prevailing personal or group ideology, suggesting greater confidence in an alternative mode of disease prevention.

SAGE recognised that these questions were largely drawn from studies in high-income countries and need more global validation, but were still a valuable starting point.

United States

One of the first and few validated surveys specific to understanding reasons for vaccine hesitancy was by Opel et al. at the University of Washington (USA). The researchers developed a measure called the Parent Attitudes About Childhood Vaccines survey (PACV), which adapted items from previous surveys on health beliefs, then tested them with focus groups to produce additional items, submitted them to a panel of immunisation experts for any further revisions, and finally

pre-tested the PACV with a group of parents. The result of this process was an 18-item survey encompassing four domains: immunisation behaviour, beliefs about vaccine safety and efficacy, attitudes about vaccine mandates and exemptions, and trust.⁵ A further study⁶ validated the survey, and also found a high degree of concordance between the PACV administered at baseline and at eight-week follow-up.

Another survey of parental attitudes in the United States⁷ found dynamics very similar to those observed in Europe. Kennedy et al. found that 85% of parents surveyed listed healthcare professionals in their top three information sources; Forty-six percent turned to family members, 22% referred to their friends for information and 24% of parents listed the Internet in their top three sources – a significant increase compared to 10% mentioning the Internet in a similar survey the previous year. The authors add that although the Internet is widely used, it is less influential than other sources, and used primarily to supplement other information.⁸ Kennedy et al. also report that lack of time is a major challenge for health providers seeking to encourage patients to vaccinate.

The most prevalent concerns reported were that children generally received too many vaccines in their first two years of life (34%) and that this caused their children pain (38%). Thirty-two percent believed vaccines caused children to get fevers, 30% believed they could cause disabilities like autism, 26% thought they contained unsafe ingredients, and 17% said they were not tested enough for safety.

Importantly, the authors found that many parents who had such concerns vaccinated their children anyway.

Europe

A recent review⁹ of studies of vaccination attitudes sheds light on survey findings in Europe over the past five years, both regarding the general public and health providers. The research reviewed consisted mainly of surveys and questionnaires, as well as some focus groups, interviews, and experiments, and a set of market research data provided by Vaccines Europe.

This research review found that fear of adverse side effects and vaccine safety were by far the most commonly-cited reasons for vaccine hesitancy among the general public. Strikingly, this was also the most commonly cited reason by healthcare professionals for not getting vaccinated themselves, and was one of the two most common reasons (along with lack of time) that health professionals gave for not vaccinating their patients.

The evidence consolidated by Yaqub et al. builds a strong case that, at least in middle-high income countries, vaccine hesitancy and refusal is not simply an issue of inadequate information or education, but instead a conscious decision among the well-educated where access is also not the dominant barrier.¹⁰ The perceived information-related problem was identified more as an issue of trust and confidence in information sources. Perceptions among non-vaccinators included concerns that government decisions about vaccines are over-influenced by vaccine manufacturers.¹¹

Although healthcare providers remain the primary influencing source of information about vaccinations, the research analysed by Yaqub et al. indicates that many European

doctors feel that patients today are more sceptical than they were only a few years ago. Friends and family also play a strong role in influencing vaccination decisions. Unsurprisingly, users of "complementary" or "alternative" medicine were significantly more likely to refuse vaccination.¹² Doctors themselves reported having too little time to discuss the importance of vaccination with their patients, even when they agreed they had a responsibility to do so.^{13, 14} Yaqub et al. also observe that doctors who become frustrated with refusing patients sometimes stop providing care to their family, an action unlikely to increase patients' confidence.

Provider confidence

Numerous studies confirm that parents' vaccination decisions are strongly influenced by their healthcare providers.^{15, 16} While this can be a positive influence for parents' vaccine decision-making, some providers may themselves harbour doubts about vaccines, which can be a powerful negative influence.¹⁷ Indeed, a growing number of surveys report low confidence in vaccination among healthcare workers, especially nurses.^{18, 19} Given the influence that providers have over their patients' vaccination outcomes, these figures are worrying.

This is corroborated by a systematic review²⁰ in which all 15 studies included found that intentions to vaccinate were higher when healthcare workers had greater knowledge about vaccines, and when their beliefs more closely aligned with the scientific evidence. Improving medical training in this area may be useful in increasing providers' confidence.

One issue of particular salience in high-income countries is the prevalence of homeopathy or naturopathy, since vaccine-hesitancy is so often linked to concerns about the artificial substances used in vaccines, or the idea that it is better to gain immunity by exposing oneself to disease than to be "unnaturally" immunised. A study²¹ of paediatric vaccination in the US found that children enrolled with naturopathic practitioners were significantly less likely to have received MMR, chickenpox, diphtheria/tetanus, and HiB vaccines, and significantly more likely to be diagnosed with a vaccine-preventable disease, compared to children not enrolled with a naturopath. Another US study,²² focusing on adults, found that chiropractic users were less likely to receive flu vaccines, but found no association with other alternative therapies and vaccination status.

However, a more recent study²³ conducted in Germany, suggested that the association between alternative treatment and non-vaccination may be a result of non-vaccinating families selecting alternative practitioners: 61% of MMR-refusing parents preferred doctors with alternative medicine degrees (compared to 22% of MMR-vaccinating parents), but doctors trained in homeopathy achieved paediatric vaccine coverage rates similar to those practicing only scientific medicine. So, although parents who believe in homeopathy are much more likely to refuse MMR vaccination, there is no evidence that homeopathic practitioners encourage their patients not to vaccinate.

There are a wide variety of resources for health providers engaging with vaccine-hesitant patients. For example, narratives and anecdotes may be helpful in discussing

Gallup poll shows both changed and persistent public perceptions of vaccines

A March 2015 survey⁶⁶ of 1,015 US adults illustrates how perceptions of vaccines have changed since 2001 – and how they have remained the same. The great majority of Americans still place great value on vaccination, although fewer believe they are “extremely important,” and opponents of vaccination appear to have increased. The proportion saying vaccines are more dangerous than the diseases they prevent increased from 6% in 2001 to 9% in 2015.

The 2015 poll also found that 6% of respondents believed vaccines cause autism in children, while 41% believed they did not, leaving 52% who were unsure. This indicates that the balance of public opinion strongly favours vaccination, but also suggests a precarious situation: a public controversy could tip the “unsure” respondents away from vaccinating. Indeed, even the “unsure” may hesitate or refuse vaccination because of their uncertainty, and future polls should ask about hesitancy and refusal specifically. In any event, these statistics clearly support public engagement strategies

geared at the uncertain majority, rather than the anti-vaccine minority. Additionally, belief in the autism myth was stronger among younger respondents and those with children under 18, but was not related to reported exposure to negative claims about vaccines, supporting the interpretation that trust in vaccines is not a simple product of information exposure.

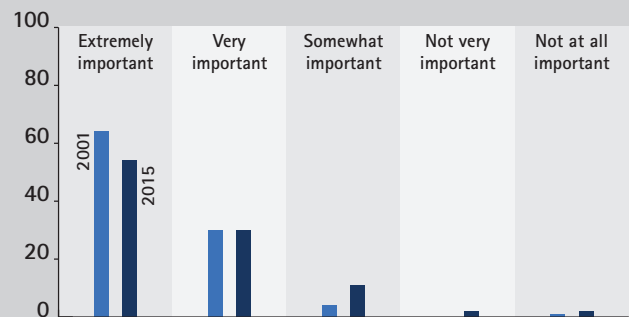


Figure 4: Importance of vaccination

vaccination with patients, since although they are poor evidence by scientific standards, they can be useful tools for translating quantitative information about safety into lay language.²⁴ Since time is often a limiting factor in such engagements, it can be useful to provide informational fact-sheets for patients to take with them.²⁵ It is also wise to distinguish between patients who are abject refusers and those who are only hesitant or cautious, and tailor the discussion appropriately.²⁶ Further in-depth guides to communication in these scenarios are also available, such as Healy & Pickering's 2011 publication.²⁷

HPV vaccine: When public, provider and political confidence all matter

By the end of 2013, 55 countries around the world had introduced HPV vaccine,²⁸ with three-dose coverage as high as 86% in the UK and 71% in Australia while only 37% in the US. In Rwanda, where HPV vaccine was introduced in 2011, acceptance was high with the first rounds achieving 95% coverage.

Both the UK and Australia were not without challenges in building confidence, but their prompt and transparent responses to reported adverse events following HPV immunisation preempted potential confidence crises. In 2007, Australia was faced with an episode of mass psychogenic illness following HPV vaccination of 26 girls at a Melbourne school,^{29, 30} but managed the response well.³¹ In another instance, following the death of a young girl near the time of her HPV vaccination in the UK, immediate public statements from health officials expressed sympathy and concern while investigating the case. When the investigation found that the death was unrelated to the vaccine, rapid engagement with the media helped quell concerns and negative media coverage, despite efforts by anti-vaccination groups to capitalise on the incident.^{32, 30}

HPV can be a particularly controversial vaccine, preventing a sexually-transmitted infection, and touching sensitive issues around sexual behaviour. In other countries various issues have

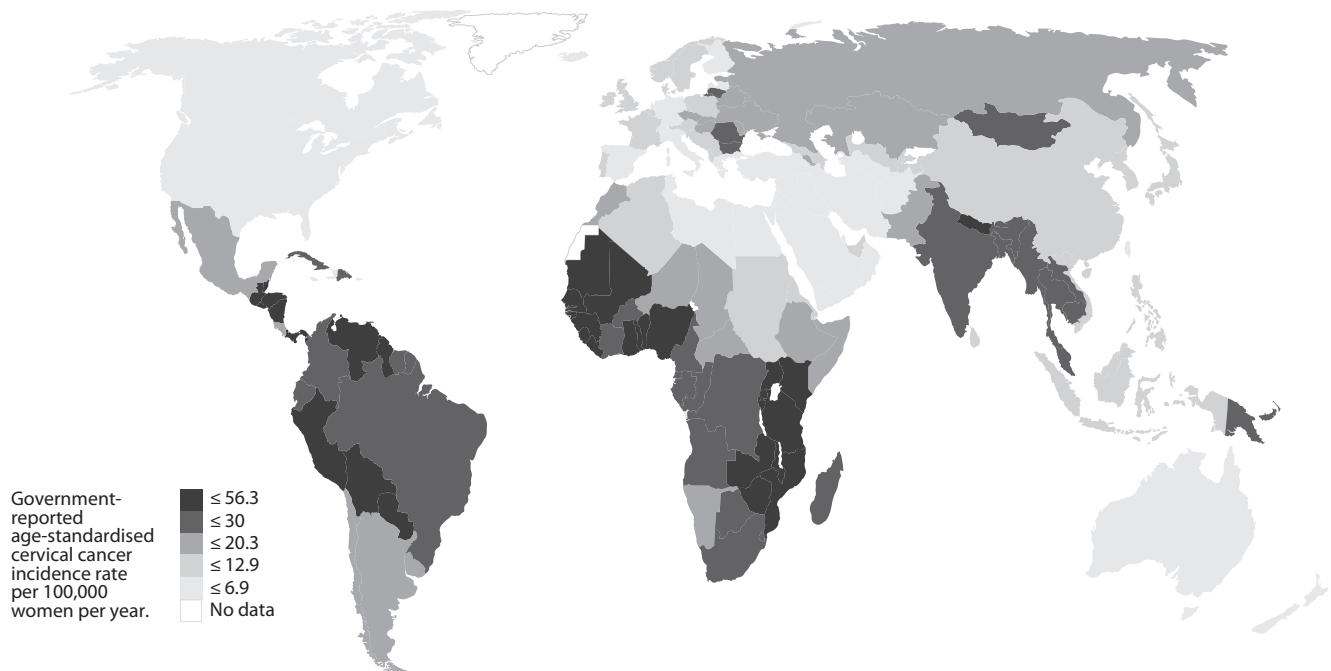
arisen including sterilisation rumours raised by male teachers participating in a qualitative study of HPV vaccine acceptability in Tanzania.³³

Following the 2006 approval of Merck's Gardasil vaccine in the US, for example, 25 states moved to make immunisation mandatory for girls attending school. This provoked controversy, in part because of concerns about it prompting promiscuity, while others saw the mandate as a governmental intrusion on private autonomy. As a result of these complications, only two states had mandates in place as of 2010.³⁴

Such concerns around sexuality are widespread. A survey of physicians and parents in Korea, Malaysia, Taiwan, and Thailand, for example, found that mothers often associated HPV with promiscuity and felt the vaccine was inappropriate because their daughter was unmarried, or simply too young (even more expressed concern that the vaccine was too new, and might have negative side effects). Physicians, meanwhile, admitted not promoting HPV vaccination because they felt unprepared to deal with the sensitive questions that would come up.³⁵ A mixed-methods study³⁶ exploring prospects for introducing HPV vaccine in low and middle income countries reported that socio-cultural issues surrounding sexuality were actually a smaller barrier than expected, while health system capacity and political priority were more substantial impediments. However, it is conceivable that socio-cultural concerns will become more visible as programmes are rolled out, and this aspect should not be disregarded in policy-making in these settings.

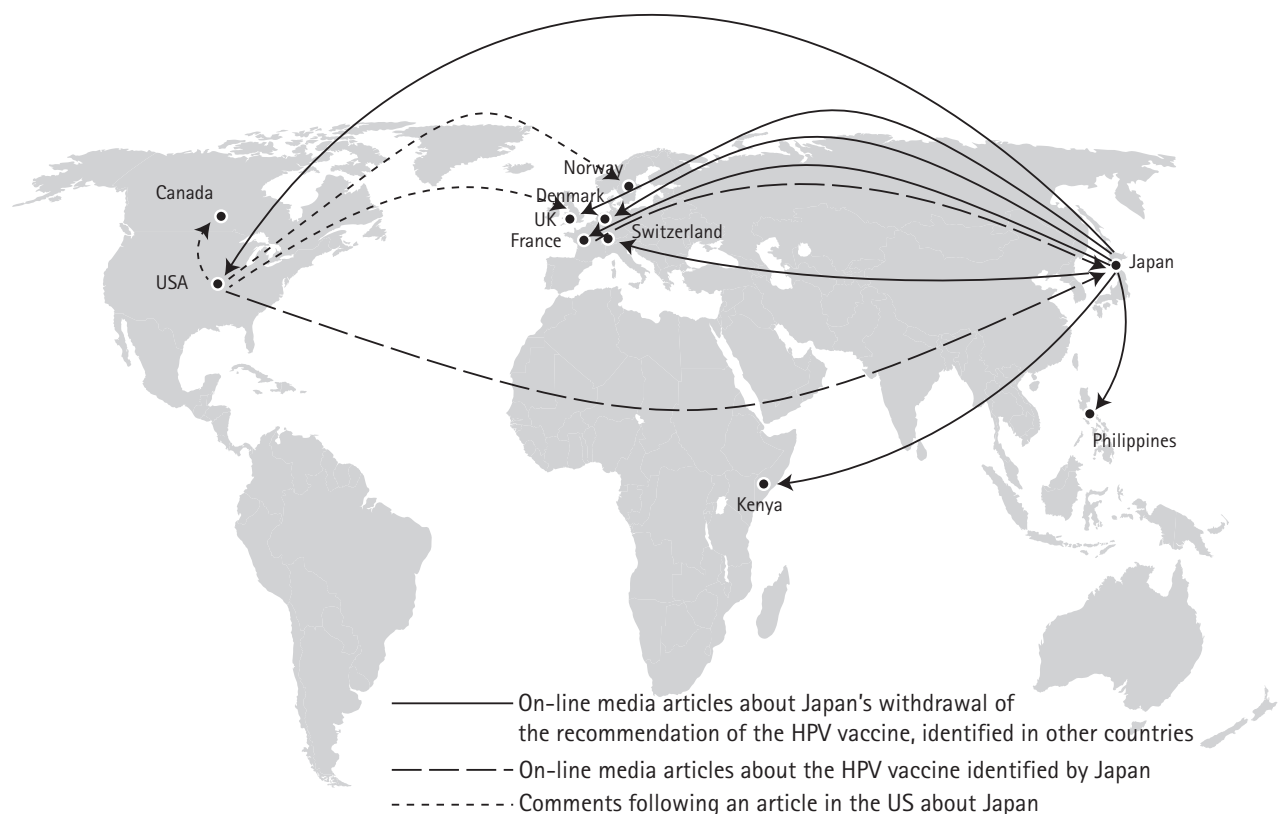
While politicians' confidence has been the anchor behind successful HPV immunisation programmes, political confidence in HPV vaccination has wavered in some settings. In 2010, for instance, the government of India suspended HPV demonstration projects in Gujarat and Andhra Pradesh states in response to memoranda and sustained pressure over several months from a broad coalition of civil society groups. The groups were demanding more participation in the decision-making about HPV policies and programmes, and questioned why vaccination was prioritised over cervical screening. The

Figure 5: Cervical cancer incidence rates worldwide



Source: Adapted from: Crow, J.M. 2012. HPV: The global burden. *Nature*, 488(7413), pp.S2–3. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/22932437> [Accessed 18 March 2015].

Figure 6: The global spread of HPV rumours



Map showing global transmission of: 1) Information about other countries' HPV situation reported in the Japanese media; and 2) reporting and discussion on the Japanese suspension of the HPV vaccine recommendation outside Japan from January to July 2014.

Source: Larson, H.J. et al. 2014. Tracking the global spread of vaccine sentiments: The global response to Japan's suspension of its HPV vaccine recommendation. *Human Vaccines & Immunotherapeutics*, (November 2014), pp.1–8. Available at: <http://www.tandfonline.com/doi/abs/10.4161/21645515.2014.969618> [Accessed 14 November 2014].

The 2009 H1N1 pandemic: Lesson for the future?

On 11 June 2009 WHO Director-General Margaret Chan declared H1N1 influenza to be the first pandemic of the 21st century, noting that "No previous pandemic has been detected so early or watched so closely, in real-time, right at the very beginning."⁴⁹ A vaccine was rapidly developed, and the pandemic became the object of sometimes alarming global media attention.^{50,51,52,53,54} Surprisingly, however, H1N1 vaccination coverage fell far short of targets around the world, both in the general population and amongst health professionals.^{55,56,57,58} A global systematic review found that key drivers of non-vaccination included perceptions that H1N1 did not present a personal threat, and a belief that the vaccine was unsafe – linked to a perception that it was developed too quickly.^{55,63,64}

Other local political dynamics and pre-existing doubts further influenced confidence in the vaccine. The Turkish public, for example, became divided along political lines on the question of vaccination. In the early months of the pandemic, the Turkish Health Minister warned of thousands of potential deaths, moved to import a large shipment of vaccines for a national vaccination campaign, and announced that non-vaccination would be treated as a crime. The Minister then came under attack from Osman Durmus, an opposition party spokesman, who claimed H1N1 was not as dangerous as seasonal flu, and accused the government

of wasting nearly US\$ 500 million on vaccines. This led to several months of protracted public debate, at the end of which "...the vast majority of the Turkish public refused to get vaccinated, and even the Prime Minister himself felt it necessary to announce his decision to refuse vaccination."⁵⁹

In a study with French-speaking residents of Switzerland, participants expressed overconfidence and a lack of concern about the H1N1 pandemic, and linked this to their perceptions of Switzerland as a wealthy nation with high standards of hygiene, a strong health system, and a responsible, disciplined, and educated public.⁶⁰

Historic memories influenced others who remembered the 1976 US swine flu pandemic that never arrived, and whose vaccination campaign left some vaccinees with Guillain-Barre syndrome.⁶⁵

Finally, the sudden appearance of both disease and remedy, "out of thin air," made the pandemic fertile ground for allegations of conspiracy prompting accusations that public health authorities, including WHO, and the pharmaceutical industry exaggerated the H1N1 threat in order to sell more vaccines.^{59,63,61,60}

The reality was that the H1N1 pandemic was a real threat with an unknown outcome. The challenge for the future will be build vaccine confidence in the face of uncertain, but very real risk.

What is the Vaccine Confidence Index?

The Vaccine Confidence Index (VCI) is an international survey-based measure of confidence in vaccines and immunisation programmes, which permits comparison across countries.

The VCI dataset will be continually expanding to include more countries. All VCI surveys contain the same foundational metric: the confidence score. Confidence scores are derived from Likert-scale responses to the question(s), "How much confidence do you have in (the health system, the immunisation programme, vaccines...)".

Respondents with children under five years old are asked whether they have ever hesitated to have their child(ren) vaccinated, and whether they decided to vaccinate or not. This permits validation of the impact of confidence on respondents' ultimate vaccination decisions, and observation of variations in the relationship between sentiment and behaviour.

The VCI survey also probes respondents' confidence in the larger institutions and programmes through which immunisation is provided, such as the national health systems, immunisation programme and health workers, as well as investigating and comparing confidence in immunisation programmes to other health services, such as emergency services and family planning.

The VCI is further enriched by data on respondents' socio-economic status and other demographic data. The confidence score is designed to be comparable over time and

across populations around the world to bring a more global perspective to an issue for which there are a growing number of local studies, but with highly varied methodologies. The VCI is expected to provide signals of vaccine confidence issues, for which more in-depth local studies will be needed to inform appropriate interventions. The purpose of the VCI is not to replace qualitative research. On the contrary, we hope that the VCI will help guide qualitative researchers to regions and populations needing further investigation and response.

The VCI can also help track progress in confidence around the world over time. In combination with media tracking technologies, the VCI may also serve as an early-warning system, detecting confidence issues and prompting rapid responses. Above all, the VCI is a tool which has the potential to enrich our understanding of the global dynamics of vaccine confidence, and ultimately help avert breakdowns in vaccine confidence before they disrupt immunisation programmes and progress.

Vaccine Confidence scale

None at all	-2
A little bit	-1
Don't know	0
Somewhat	+1
A lot	+2

government's initial non-response had probably done more harm than good, heightening perceptions that the government was more interested in listening to pharmaceutical companies and international NGOs than to its own people.³⁷

Although sexuality was not a major issue in this stoppage, it was raised in qualitative interviews separately conducted in 2008 with Indian physicians, who found it difficult to talk to parents about health topics related to their children's sexuality, and therefore rarely recommended the HPV vaccine.³⁸

In another case where a government was pressured by activists to interrupt an HPV vaccine programme, Japan suspended its HPV vaccine recommendation in June 2013, following reported adverse events following HPV vaccination in young women. Although the problem seemed real enough, no distinct relationship with the vaccine could be found. The Japanese government therefore continued to provide the vaccine, but stopped active recommendation of HPV vaccination, pending further research. Despite the continued availability of the vaccine, the suspended recommendation led to the drop in vaccine coverage from well over 70% to under 5%. And, although the Japanese Ministry of Health did create a Q&A webpage that provided information on the vaccine's safety, its ambiguous policy nonetheless fostered confusion, and both local patient groups and international social media networks continued spreading anti-vaccine sentiment.³⁹

The Japanese story was picked up by media outlets in the UK, Denmark, Kenya, Switzerland, France, and the Philippines. One American commentator praised Japan's "demonstration of genuine concern for the health and well-being of their citizens," implying that governments still recommending the HPV vaccine did not share this genuine concern. These US articles, in turn, gained attention in other countries, such as Norway, Canada, and the UK.³⁹ In January 2015, the HPV vaccination recommendation was still suspended in Japan.

In September 2014, in another case in the northern Colombian town of El Carmen de Bolívar, HPV vaccinees reported numbness, fainting, paralysis, and seizures, and the local hospital was soon overwhelmed by hundreds of cases strikingly similar to those in Japan. President Juan Manuel Santos, in trying to calm concerns of a biological link with the vaccine, instead aggravated tensions when he referred to the event as a "phenomenon of collective suggestion."⁴⁰ Sufferers again took to social media to make their case, posting videos of their symptoms, inflaming the events into a media sensation. Unlike the case in Japan, the Colombian government, and particularly the Ministry of Health, stood by their confidence in the safety and efficacy of the HPV vaccine and the vaccine recommendation was not withdrawn following the events in El Carmen de Bolívar.

Real-time media monitoring ('fast data')

Media and social media surveillance can offer real-time monitoring of the public pulse, providing an opportunity to anticipate emerging issues through the rapidly expanding repository of "digital traces" left by electronic communication.

News media, and other forms of journalism, such as blogs, offer accessible and real-time account of events worldwide, and analysis of these accounts can be used to detect changes

in public confidence⁴¹ as well as identify known prompters of public questioning – such as adverse events, new vaccine introductions, new research or contextual events.

Other examples of digital media analysis include hourly logs of page views available from Wikipedia, for example, which have been used effectively in several studies to detect public sentiments and concerns based on fluctuations in the general public's interest in particular topics.^{44,45,46} A similar method has also been successful in monitoring and forecasting infectious disease trends worldwide.⁴⁷

Social media monitoring technologies permit direct measurement of public sentiment expressed by members of the public, rather than after being mediated by journalists and editors. Data from the Twitter social media service, for example, have been used⁴² to study the evolution of public sentiments relating to the 2009 H1N1 "swine flu" pandemic. This study used sentiment analysis to assess the "polarity" of 477,768 Tweets as being positive, negative, neutral, or irrelevant to the H1N1 vaccine. Sentiment analysis of this large dataset was achieved using a machine learning approach, wherein a subset of tweets coded by human participants was used to train an automated classification algorithm. These tools, and tools like them, can be of great value in measuring vaccine confidence.

The investigators compared their estimates of sentiment against vaccination coverage data provided by CDC, and found a strong association between the traditional survey-based method and their social media tool. Furthermore, the authors analysed⁴³ the opinions expressed through social networks, and found that like-minded users were more likely to cluster in common networks and share messages among themselves rather than exchanging messages with opposite-minded users. Furthermore, the authors estimate that if real-life social networks mirror virtual social networks, and unvaccinated individuals clustered in real life to the extent observed on Twitter, the likelihood of large outbreaks of disease would be greatly increased. Thus, the social organisation of vaccine sentiments has consequences not only for perceptions, but also can have real-world consequences for disease transmission and its public health impacts.

The best media monitoring studies tend to focus on discrete outbreaks of vaccine-preventable disease, since these receive more news coverage and provoke greater public commentary than routine immunisation usually does. One such study concerns the May 2013 measles outbreak in the Netherlands among orthodox Protestants, who generally refuse vaccination on religious grounds.⁴⁸ This research, conducted between April and November 2013, analysed tweets and messages on other social media platforms (such as Facebook), as well as online news articles, to assess the types of opinions expressed in these texts, and compare the change in the volume of commentary to the actual epidemiologic curve of the outbreak.

The study found that peaks in volume of all three types of media corresponded to official announcements about the measles outbreak, rather than the actual number of measles cases in a given week. This indicates that media analyses should not be interpreted as a reflection of the population's direct experience of an epidemic. Rather, tweets and social media reflect the public's response to official statements and other

Figure 7: Comparison of relative proportions of weekly tweets, social media messages, and online news articles to measles cases from April 15 to November 11, 2013.

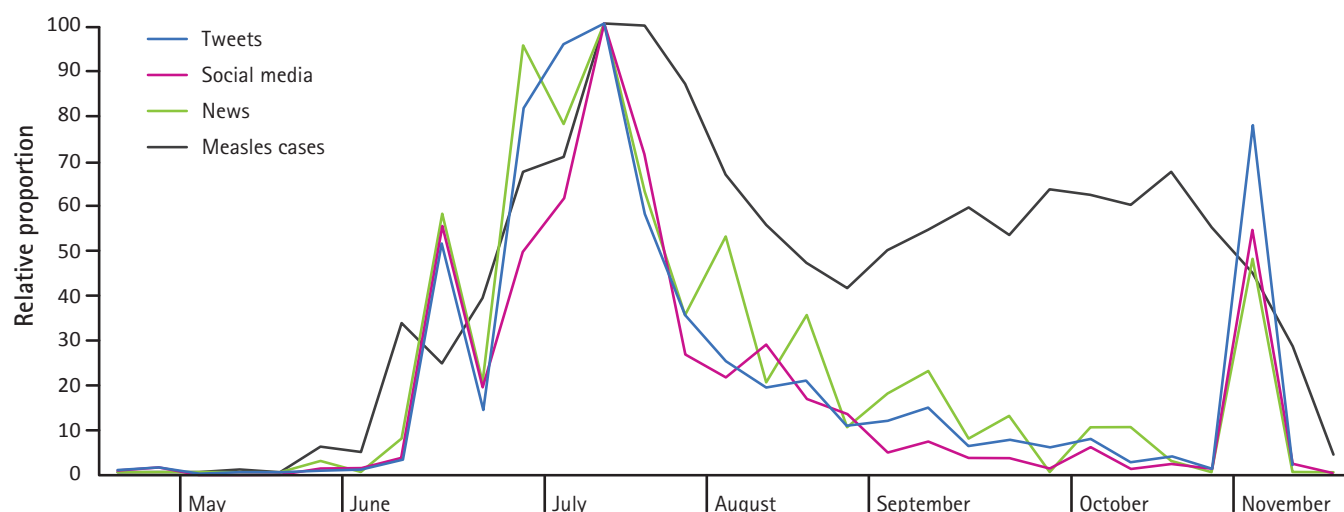


Figure has been scaled to the highest peak in week 28 for all four data sources. This peak was assigned a score of 100.

Source: (Also for Table 5 below, which breaks down media commentary by type and topic). Adapted from Harmsen, I.A. 2014, p.123. *Vaccinating: Self-Evident or Not? Development of a monitoring system to evaluate acceptance of the National Immunization Program*, Ridderprint. National Institute for Public Health and the Environment, Netherlands.

Table 4: Topic of coded measles tweets, retweets, social media and news articles

Topic	Tweets (N=136)	Retweets (N=60)	Social media (N=467)	News articles (N=282)	Total (N=945)
Measles incidence	41%	23%	20%	53%	33%
Measles prevention	17%	28%	20%	27%	22%
Perceived risk	10%	5%	19%	5%	11%
Orthodox Protestants	15%	15%	13%	5%	11%
Critical towards vaccination	2%	7%	11%	6%	8%
Other	12%	12%	11%	1%	8%
Trust and role of institutions	3%	10%	6%	3%	5%

events reported in the mainstream media narrative. This need not undermine the value of media monitoring, but it is an important distinction to understand.

Furthermore, the coding of text topics and sentiments (shown in Figure 7 and Table 4) allowed researchers to characterise the dominant messages spread through these media. The majority of tweets and social media messages on the topic of measles incidence and prevention were for information-sharing. An additional subset expressed frustration with orthodox Protestant parents who did not vaccinate their child. In fact, 48% of messages on the topic of orthodox Protestants were sentiment-coded as "frustration". In the more general topic of criticism of vaccination, 43% of social media messages were neutral and 39% exhibited frustration. Messages related to the topic of perceived risk

tended to minimise the riskiness of measles rather than express concern about it. Social media messages about trust and public health institutions were coded as 53% frustrated and 30% neutral.

Media monitoring is an emerging field, with many questions still to answer. However, social media permits tracking of sentiment with unprecedented spatial and temporal resolution and can serve important early-warning functions for health authorities, and in combination with other approaches such as surveys and qualitative research, can be a valuable contribution to characterising public confidence in vaccines and immunisation.

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Conclusion and recommendations

This report has examined the state of vaccine confidence at the beginning of the 21st century – a window that may be historically brief, but nonetheless abounds with new challenges as well as innovations.

This is an age when the ancient politics of personal choices and freedoms are colliding with scientifically-based public health strategies. For some, public health interventions such as immunisation are viewed as "global public goods", while others perceive vaccination as an infringement on personal liberties.

The cases discussed in earlier chapters teach us that vaccine confidence is not just about vaccines. Example upon example illustrates the manifold forms that doubt and distrust can assume – boycotts, bans, protests, and all manner of grievances – many of which are well beyond the realm of medical science, but driven by politics, values and emotions embedded in the people and societies which medical interventions seek to serve. For this reason, health science alone cannot achieve the aspirational goals of immunisation programmes, and engagement is needed well beyond the health sector.

Having said that, it is also clear that confidence-building within the health sector itself is important. Providers need to feel confident in the safety of the vaccines they are recommending, and confidence in answering the growing number of questions from parents. Providing an environment that helps build confidence is especially important for those health providers who are delivering vaccination in dangerous areas such as North-West Pakistan, where they have been targets of violence, in conflict-ridden areas such as Syria, or amid humanitarian disasters such as the Ebola outbreak in West Africa, where their risks come from outside the immunisation programme, but nonetheless can challenge self-confidence.

The third dimension of confidence discussed in this report is the confidence of politicians and policy-makers to stand up for the science behind vaccines and vaccination while remaining responsive to the concerns of the public. Although there can be no compromises when it comes to standing up for the scientific evidence supporting vaccination, this should not prevent public health authorities from being flexible and making necessary and appropriate compromises in how vaccines are delivered to make them more acceptable.

A survey¹ of American paediatricians showed that, like politicians who may bend to public emotion and contradict science to keep their constituency, some physicians will go against their medical understanding of what is best for the child, in order to maintain their relationship with the child's parents. Indeed, the primary reason physicians gave for agreeing against their rational understanding was because they felt that it would build trust with the families (82%) and that the families would be less likely to look for another doctor (80%).

Similar sentiments have been expressed in low-income

countries, where health workers expressed concern about starting to use new vaccines if there was not a guaranteed long-term supply as they might lose the confidence of the families they serve.

This trust dimension which is so important to the provider-parent relation resonates with the tension faced by many politicians and policy-makers who are increasingly caught between scientific evidence and wanting to keep their trust relations with their public. A number of these decision-makers have opted for keeping the public trust against the scientific advice, such as the Japanese government's decision in 2013 to suspend proactive recommendation of HPV vaccination (albeit continuing to provide it on demand) in response to public concerns expressed about the vaccines.

These cases underscore the power of trust as a determinant of decisions at public, provider and political levels.

Trust in vaccines is also closely linked to the institutions and individuals who provide them, as shown in some of the research presented in this report. Trust in health and immunisation programmes is a clear driver of vaccine confidence.

A research agenda

Vaccine confidence is not just about the vaccine, but also about relationships with the health provider and trust in the politicians and policy-makers. Confidence is also influenced by social and political context, which is dynamic and changing. All of these dimensions need to be understood and monitored over time.² There have been a number of forums where research agendas have been proposed in the area of vaccine confidence and hesitancy.

MOTIV: Motors of Trust in Vaccination

In 2010, another initiative called "MOTIV" convened a think tank to examine the "Motors of Trust in Vaccination" from multiple disciplinary perspectives. The outcome of the think tank was published in a paper, "A Multidisciplinary Research Agenda for Understanding Vaccine-Related Decisions"³ where a research framework was presented. The paper also presented a number of key research questions needing further investigation:

- Which cognitive processes mediate vaccine decision-making and what are their relative roles in different contexts?
- How does engagement with the various publics influence the level of trust in vaccines, vaccinations and vaccination-promoting groups or organisations?
- Which public engagement strategies within the areas of vaccination decision-making and broader healthcare have achieved their goals, and how and why have they achieved their goals? How does/should communication and engagement change according to culture, geographical region or broadcast channel?

Other, additional research questions are emerging, particularly in the area of research methodologies, as discussed in Chapter Three, to investigate the complex arena of vaccine confidence and the psychological, social and political influences that define it.

Key recommendations

There are a number of lessons learned woven through this report, but here we highlight some of the critical points to consider when introducing a new vaccine or when trying to address a routine vaccination that has lost the confidence of the public or providers:

- **When introducing a new vaccine, think beyond the vaccine and the vaccination to consider the contextual historical as well as current societal and political factors** that could influence public confidence in the vaccine and the vaccination programme. Sometimes the solution lies outside the vaccination programme.
- **When countering a negative rumour or conspiracy theory, 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 the face 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 evidence. Respect beliefs, while trying to find other ways to make vaccination acceptable.
- **Target engagement efforts at vaccine-hesitant groups and those who are "sitting on the fence"**. They are reluctant, seeking answers to their questions, and are yet undecided and need the support to make the most informed decision.
- **Vaccine confidence is not just about vaccines** – confidence in and by providers and political leaders is key.
- **Health science alone cannot achieve immunisation goals** – political and social scientists are needed along with risk and decision-making experts.
- **Confidence building within the health sector itself is important** – providers need to feel confident in the safety of the vaccines they are recommending and confidence in answering the growing questions from parents. Providing an environment that helps build confidence is also important for health providers working in conflict or other humanitarian situations where their lives are at risk.
- **Never underestimate the importance of listening and public engagement**. This will take different forms in different settings, but is universally vital. The listening and engagement process needs to start from the planning stages and throughout implementation of vaccination programmes. Sentiments can, and do, change. Listening and engagement needs to be ongoing.
- **Trust is built over time, brick by brick, from individual acts of goodwill**. It requires genuine care for and accountability to the general public. The task that stands before public health leaders is to listen to their publics, hear their concerns, and take them seriously.

Protecting Public Trust in Immunisation Some key recommendations

- Increase the number and diversity of citizen members on advisory bodies without reducing scientific expertise.
- Give the public sufficient information and adequate time to understand the rationale for any new vaccines before embarking on immunisation campaigns, which can be done without delaying protection.
- Engage local communities and parent groups as advocates of new vaccines.
- Avoid the hyperbolic marketing practices of overselling.
- Take the time to explain changes in recommendations and policies. Such explanations are essential for reducing charges of hidden agendas.
- Invest in research on what is truly driving parents' questions and concerns and what may be needed to earn/keep their trust in vaccines.

For full list see Cooper et al (2008)⁵

Public Trust in Vaccines: Defining a research agenda

In another initiative, the American Academy of Arts and Sciences convened a working group to develop a research agenda, and published a report⁴ "Public Trust in Vaccines: defining a Research Agenda" which highlighted three key areas for research, posing some specific questions within those domains:

1. Parental attitudes and knowledge

- When and how are attitudes and beliefs about immunisation formed?
- To what extent does vaccine hesitancy result from a broader distrust in government and science?

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 most strongly influence their decisions.

2. The medical encounter

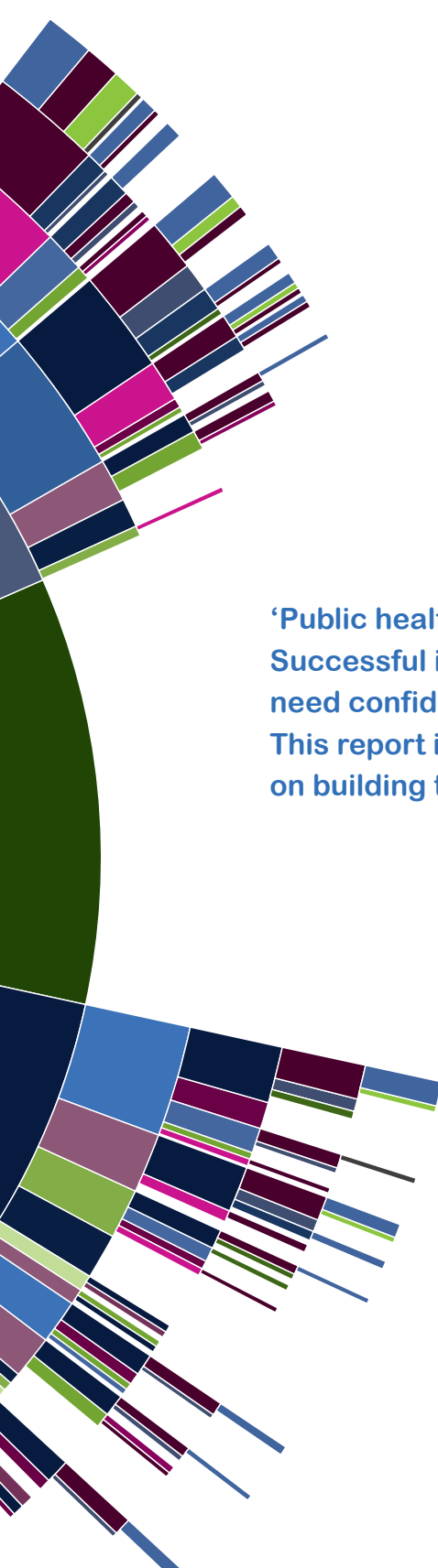
- How can providers best respond to parental concerns?
- Researchers should evaluate the effectiveness of communication strategies, including negotiation, used by clinicians when discussing childhood vaccination with parents.

3. At-risk communities

- What are the most effective ways to identify geographic communities at increased risk of vaccine-preventable disease outbreaks?
- Do social networks play a different role in these communities?
- What types of community-based interventions would have the largest effect on vaccine uptake?

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‘Public health needs public trust.
Successful immunisation programmes
need confidence in vaccines.
This report is timely, with important lessons
on building that trust and confidence.’

Margaret Chan,
Director-General,
World Health Organization