Time to talk about trust

Public trust in health research needs nurturing. How can epidemiologists help? **Sandra Alba** reports on a crucial debate

Do vaccines do more harm than good? A huge body of evidence from epidemiology would say "no", that vaccines in fact do more good than harm. Yet, despite this evidence, many high-income countries are seeing a drop in vaccination coverage and a surge in preventable disease. How do we explain this behaviour? Why are some people refusing to get vaccinated, or refusing to vaccinate their children?

Part of the problem is a growing lack of trust in research. Through the media, people are confronted with an overwhelming amount of scientific evidence, and while most of that evidence will be based on robust, well-designed research, some of it will arise from ill-designed, poorly implemented, inappropriately analysed or selectively reported studies. And when two pieces of evidence contradict each other, it can be hard for people to know which to act on.

When faced with such contradictions, rather than seeking a better understanding of science to sort good research from bad, people may instead grow sceptical of *all* research, and may be guided more by belief and opinion than evidence.

But lack of trust in research could also be the expression of a more complex societal phenomenon. A May 2019 study of 25,000 people across 23 countries covering parts of Europe, the Americas, Africa and Asia found that people with strong populist attitudes were more likely to believe in conspiracy theories, even if these were contradicted by scientific evidence (bit.ly/2tH5Cbs). As *The Guardian* reported, "25% of those who had cast a ballot for rightwing populist candidates and parties had concerns about the effects of vaccines, compared with 14% of the rest of the population" (bit.ly/2taFUj5). According to one political scientist who analysed the study data, scepticism towards vaccines and science may be driven "by anger and suspicion towards elites and experts that has also resulted in increasing support for anti-establishment political parties across Europe and beyond".

Regardless of the root cause, distrust in science is a global health issue.

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Vaccine hesitancy could potentially threaten millions of lives, mostly in low- and middle-income countries, according to the World Health Organization (bit.ly/31B5ch5).

Such considerations helped set the scene for a public event hosted by the KIT Royal Tropical Institute in Amsterdam last summer (bit.ly/2SpGZYZ) to explore how epidemiologists across the globe can nurture and, where necessary, help restore society's trust in research. Several key themes emerged.

Evidence alone is not enough

Epidemiologists need to realise that decision-making – be it at an individual level or a policy level – is not shaped by evidence alone. The Peruvian doctor and demographer Walter Mendoza says that: "At policy level, political and economic factors may be the driving forces. At individual level, a person's experience, and the experience of their families, friends and neighbours, becomes their own evidence base. Scientific evidence may only play a small role."

Roland Kielman

But there may be a way to inject more evidence into that individual, personal experience. Nicoline van der Maas, a doctor and epidemiologist at the Dutch National Institute for Public Health and the Environment, says that epidemiologists should engage with health providers – specifically, nurses, general practitioners (GPs) and paediatricians – and use these direct communication channels to share important information and gain a better understanding of the patient perspective.

"People trust their GPs," says van der Maas. "They listen to them; they value their opinions." This is borne out by a 2018 Wellcome study of more than 140,000 people from more than 140 countries, which found high levels of trust in health providers worldwide (bit.ly/2aCH4Yf). Globally, 73% of people said they would most trust a doctor or a nurse to give them health advice, with results ranging from 64% in East Asia and 68% in central Africa, to 88–89% in Europe, North America and Australia.

Focus on education, not information

While health providers may be trusted, their voices can be easily drowned out by the constant torrent of (often uninformed) opinion from social media. The influential role that this form of communication plays in people's lives was flagged as a particular cause for concern by anthropology professor Sanjay Juvekar, from KEM Hospital Research Centre in Pune, India.

With their incredible speed of propagation, social media messages can quickly supersede any public health information campaign. However, one way that public health professionals can keep ahead of the game is by focusing not only on information but also on education; and for this they need the support of epidemiologists.

Mariska Leeflang, associate professor of clinical epidemiology at the Amsterdam Medical Centre, pointed to the Informed Health Choices (IHC) network as exactly the sort of initiative to address this challenge (bit.ly/2rzItyX). In particular, she called attention to the IHC's primary school education material, *The Health Choices Book: Learning to Think Carefully about Treatments* (bit.ly/2HB6y4s), saying: "It's never too early to start teaching evidence-based medicine."

Develop a human-centric view

According to Leeflang, science, research and evidence are subject to two debates running in parallel. One is a scientific debate, in which scientists openly discuss the limitations in scientific practice and the impact of different study designs and analyses, which may lead to different answers. The other is the public debate, which is dominated by highlights – such as reported major breakthroughs – and scandals – such as researchers caught cheating or faking data and having their findings retracted.

"The public debate is mainly seen as non-scientific by researchers, and as such they would rather not engage with it," says Leeflang. But this is a mistake, she adds, because the public "does consider it a scientific debate" – and all the public sees is that researchers are unwilling to take part.

For Daniel Weibel, epidemiologist at the European and Developing Countries Clinical Trials Partnership, humility is the key to bridging the divide between the scientific and public debate. "We need to enter into an honest and humble conversation with the public," he says. "Alongside the findings and successes of our work, we need to also acknowledge and stress the limitations of what we present."

Researchers mostly focus on publications in scientific journals and have difficulties with other forms of dissemination. But finding a way to more efficiently and effectively communicate with the public is key. Indeed, as Mendoza points out, doctors and nurses work by an adage which could serve epidemiologists well. "At medical school we learned to treat people, not diseases," he says. But epidemiologists do quite the opposite – and that may be part of the problem.

As Kristien Verdonck, epidemiologist at the Institute of Tropical Medicine in Antwerp, describes it: "[Epidemiologists] are trained to focus on populations and to describe diseases in terms of percentages, averages, relative risks, etc. These types of scientific statements may not satisfy an individual person, who either gets a disease or doesn't. They may just want to know *why* certain events happened to *them*. These are legitimate questions that epidemiologists may not be able to answer."

Verdonck suggests that "listening to ordinary people's concerns and taking the time to explain what we know and to admit the many things we don't" may lead to a better dialogue with the public. In addition, Stuart Blume, a professor in the University of Amsterdam's anthropology department, says epidemiologists should collaborate more with anthropologists, "since this is the discipline which investigates socio-cultural influences on risk perception and ideas about health and illness more generally". Anthropologists study the types of issues mentioned so far, such as how beliefs, as well as trust in professionals, vary as a result of collective experience. So an anthropological perspective could introduce some of the humility that Weibel thinks is necessary.

Ultimately, change is needed

One major hurdle, of course, is that researchers have little professional incentive to engage with the public, since scientific publications remain – for many – the only metric for career progression. Therefore, if we want scientific rigour to also include an element of what Mendoza calls "societal rigour" – to nurture public trust in research – a complete overhaul of reward structures in academia is required.

Until that happens, it falls to scientists of all types – including epidemiologists and statisticians – to take the initiative and to engage willingly and constructively in the public scientific debate. ■