

Vaccine Hesitancy

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The rate of measles infections reached a 16-year high in Australia last year, mainly due to travellers catching measles overseas and passing it on to unvaccinated children after coming home. We are in serious danger of horrible diseases which had been eliminated from Australia, making a comeback due to a rapid increase in parents failing to have their children vaccinated.

The conventional term, “vaccine hesitancy” (VH) implies *hesitancy* in relation to *vaccination*, but some people are not hesitant at all but *decisive* in refusing vaccination, and some are hesitant about a specific vaccine not vaccination as such. But the term is accepted as indicating this entire field of behaviours.

Since the Christian Scientists confirmed that they do *not* have a conscientious objection to vaccination, there is now no basis for objection on religious grounds. There remain however a range of reasons behind failure to access available vaccination programs, and different responses by the community are required in each case. The Abbott government’s policy to send a ‘price signal’ by withdrawing welfare payments will work for a minority of VHers but will alienate and harden the resistance of an expanding section.

Socio-economic status and level of education have proved to be poor predictors of VH and the usual empirical-demographic and public education approaches to public health challenges have proved problematic. Policy makers do not know what to do to improve the uptake of vaccination.

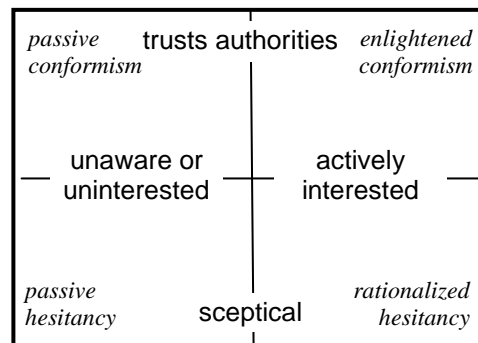
Researchers using the ideas of ‘reflexive modernity’ and ‘risk society’ from Ulrich Beck and Anthony Giddens measure responses to vaccination along two axes. The horizontal axis measures the extent to which the subject has embraced risk culture in which the world is full of unpredictable sources of danger, and “healthism” in which the subject takes active responsibility for managing their own health. The vertical axis measures the subject’s disposition to trust the entire system of expert culture and established power and authority.

Risk Culture and Healthism

On the left of the horizontal axis are people unaware of the severity of diseases like measles, smallpox, rubella, because they have never had any personal experience of them and are unaware of the need for immunization programs.

On the right are people who take an active interest in their own health and that of their children, seek out information and are strongly committed to whatever views they arrive at, positive or negative.

Positioning on this axis is questionably deemed to reflect a *personality trait*. What is characteristic of modernity is the shift towards *individual responsibility*. People no longer ascribe either their good fortune or their poverty to the prevailing political-economic system nor look to governments and authorities to help them. Governments actively promote ideologies of self-reliance, and discredit *collective* action, such as by trade unions or other kinds of activism.



Trust

Distrust of public officials is as old as civilisation, but in the past, while people may have distrusted the police or their boss, they tended to accept the word of experts, but the rational scepticism which has been the province of science for 400 years, is now turned back on to science itself and everyone thinks they are qualified scientific opinion makers. No-one believes advertisements and nor do they believe the more measured but less persuasive claims of scientists and public health officials.

At the top of the vertical axis are those who still believe the doctor will keep you healthy and scientists understand Nature.

At the bottom of the vertical axis are those who presume that genetically modified food is dangerous to world health, the government is probably lying, scientists are motivated by prospects for promotion and vaccination programs are some kind of ruse.

The "VH Compass"

The combination of the two axes produces four archetypes which can be mapped on a "compass."

Passive Conformism: in the NW quadrant are people who take no interest in vaccination issues, believing it to be either unimportant or all taken care of; unaware of the danger of diseases like rubella and smallpox or their part in eliminating them, they forget to attend clinics for top-ups and ignore news about infectious diseases. But when told that this is what they have to do, they will not suspect any ulterior motive or doubt what their doctor tells them, and try to comply. These people may possibly respond to 'price signals'.

Enlightened Conformism: in the NE quadrant are people who follow the advice of their doctors and health authorities, closely read the instructions on the packets, check that the local school is doing the right thing and actively support public vaccination programs. These people need neither threats nor propaganda.

Passive Hesitancy: in the SW quadrant are people who make no effort to inform themselves about vaccine issues but neither do they believe what the government or their GP tell them. They only trust information from their friends and neighbours.

Rationalised Hesitancy: in the SE quadrant we have that group which is truly a product of our times: they take responsibility for their own health, meticulously controlling their diet, avoiding manufactured food and taking an active interest in issues such as contamination of crops and water sources and inform themselves about vaccination issues. However, they do not regard the Federal government, far less Pfizer or Roche as sources of reliable information and believe that university research is subject to corporate influence. Because this group makes their own judgments based on evidence, they may refuse one vaccine while accepting another. It is this cohort which is of particular interest, both because it is the quadrant which is growing, and which is most resistant to public health measures such as Abbott's 'price signal'.

'Herd immunity' relies on the number of unvaccinated people remaining below a critical percentage, somewhat like the critical mass of a radioactive material beyond which a nuclear chain reaction occurs. So long as the percentage of vulnerable people is less than a critical level, an infection will eventually die out; beyond that level, transmission continues indefinitely. So vaccination is not a question of personal choice but of public safety, like the fire ban enforced during the summer months. At the same time, rational scepticism is an entirely responsible orientation: there are ample precedents for irresponsible marketing of health products and unforeseen consequences of innovative medical practices. There is no formula or universal criteria to judge the safety and efficacy of vaccination which does not rely on *trust*.

Whooping Cough vaccine scare in UK, 1977

In the early 1970s, the whooping cough vaccine was producing some unpleasant but harmless side effects. In 1977, the *Lancet* published an article suggesting that the risks of this vaccine outweighed the benefits and media coverage led to the coverage rate falling from about 75% to 40%. Controversy raged in medical press until 1981 and confidence gradually recovered, coverage reaching 90% by 1992. During this period there were no active anti-vaccination groups, which only appeared during the 1990s.

MMR vaccine scare in UK, 1998

In 1998, the *Lancet* published a paper claiming that the MMR vaccine – a combination of measles, mumps and rubella vaccines – caused autism and colitis. The claim was completely fraudulent, but the *Lancet* only fully retracted the paper in 2010. Epidemiological research conclusively ruled out the claimed association, but the claim was widely reported in the media internationally, and the belief that MMR vaccination can cause autism persists to this day. MMR vaccination rates in the UK dropped from 92% in 1996 to 84% in 2002, as low as 61% in parts of London, and has still not recovered to the 1996 level. The incidence of mumps was 37 times higher than 1996 levels in 2006, in 2008 measles was once again declared endemic in the UK, and there were consequent outbreaks in other countries.

In both these cases it was the most trusted medical journal in the world which started the scare, but it proved extremely difficult to put the genie back in the bottle.

N1H1 vaccine dispute in Europe, 2009

In December 2009, Council of Europe parliamentarian and epidemiologist Wolfgang Wodarg presented a recommendation to the Council of Europe entitled 'Faked Pandemics: A Threat to Public Health' claiming that the WHO had over-reacted to the threat of the N1H1 virus. After months of debate, the Council of Europe passed a motion decrying WHO's public reaction to H1N1. Subsequent experience tended to confirm that the Council of Europe had been correct; scientists judged that a pandemic had not developed, there were questions over the efficacy and safety of the H1N1 vaccine and the threat was not serious enough to warrant mass vaccination, which carries its own risks. The anti-vaccination voice proved to be the most worthy of trust.

Decisions on vaccination cannot sensibly be understood as individual decisions. The Council of Europe and *Lancet* are not simply 'sources of information' on which an individual can draw. An individual is a participant or not in a discourse prior to the reception of an argument framed within that discourse, and will accept or reject the argument accordingly. Who to trust? is not a question which can be answered from outside discourse; it is always decided *within a discourse*.

In Australia, the average vaccination rate at 5-y-o is 91.5%. This leaves 75,000 children vulnerable, 15,000 of them registering a conscientious objection, distributed across the country. The 3 postcodes with lowest vaccination rates at 5-y-o are:

- 2481 Byron Bay, NSW North Coast 66.7%
- 2483 Brunswick Heads, NSW North Coast 70.2%
- 2000 Sydney CBD 72.1%

These areas are well-known for having significant sections of the population which can be described as well-educated, favouring 'alternative' life-styles and distrustful of authorities, squarely fitting the profile of 'rationalised hesitancy'. Areas with the highest numbers of children registering with a conscientious objection emphasize the same demographic.

The highest rates of vaccination are in far north Queensland, exposed to transmission of diseases across the Torres Strait. In Indigenous communities, rural areas and working class suburbs, the 5-y-o vaccination rate is nowhere under 90%. So it is clear

that the problem with vaccination levels is with the “rationalised hesitancy” of the SE quadrant, whether or not living in the “life-style” postcodes.

In the UK, one could say that the public’s loss of confidence in the whooping cough vaccine was a rational reflection of the state of scientific knowledge in the 1970s. But whereas authorities could restore confidence in a vaccine in 1992, a few years later they proved unable to do so.

Modernity has fostered certain social attitudes which colour public health problems in a distinctive way, but the strongly localised concentration of refusal of vaccination suggests that the problem is not one of attitudes and personality types, but that individual responses to modernity but are *socially constructed*.

Research has shown that being critical of vaccination is correlated with preference for natural childbirth and the use of alternative therapies such as acupuncture, homeopathy and naturopathy. This, combined with correlation with living in the “life-style” areas or the inner cities of the major capitals confirms that VH is part of a *wider* attitude to health.

Giddens and Beck give us a plausible picture of the social changes which have fostered distrust of experts and individual ‘entrepreneurship’, but if anti-vaccination views are taken to passively reflect the conditions of modernity, how can we *change* this situation? These social conditions will continue, so presumably so will the attitudes characteristic of these conditions. The ‘life politics’ of ‘reflexive modernity’ is not a spontaneous response to modern social conditions but a product of projects which have arisen from modern conditions and together *produced* modernity as we know it.

None of the archetypes represented in the VH Compass are actually satisfactory stances, including the ‘balanced position’ at the centre-point. The WHO, the *Lancet*, the Council of Europe and so on are also subjects that could be mapped on to the Compass – there is no dimension measuring the *actual* level of expertise of the subjects, all of whom are taken to be laypeople. Isn’t this reducing the problem to an objective process in which ‘reflexive modernity’ simply reproduces itself? If we are going to characterise subjects according to dimensions, is it believable that there are only *two* dimensions? For example, isn’t trust specific to *who* is trusted – religious leaders, passers-by, neighbours, scientists, pharmaceutical companies, the media, Stanley Milgram, politicians? And is ‘entrepreneurship’ really so thoroughly individualised, or do people still seek to control the events affecting their lives collectively with others if not governments? In any case, one and the same person would occupy different positions on the Compass in relation to particular vaccines.

As valuable as the insights of ‘reflexive modernity’ may be, we are still left with an individual making rational decisions on a background of given social conditions with no clue as to how to deal with rationalised hesitancy. Asking them to ‘listen to reason’ has not worked so far.

Rather than taking the rational hesitancy of a section of the population as an individual response to social conditions, we need to know *how* parents actually acquire their view, and *how* the population’s trust in the scientific and medical establishments was lost to know if and how it can be restored.

Stuart Blume has studied how parents have formed their attitudes to vaccines, and examined the contribution which the medical profession have made to this loss of trust. The history of earlier health activism such as Women’s Health Movement and the HIV/AIDS movement make it clear that relations between the medical establishment and the population has been actively produced and is not a passive, individual reflection of social conditions.

Blume says that anti-vaccination social movements arose in the 19th century when compulsory mass vaccination programs were first introduced in Europe and America.

These movements were generally led by the promoters of alternative therapies whose projects were threatened by mass immunisation, and they found allies in both the working class and middle class because of the compulsory aspect of the vaccination programs. Compulsory vaccination was a challenge to the workers' movement whose project, after the failure of Chartism, was *independence* from state regulation, welfare and philanthropy and to the liberal middle class whose project was the extension of personal liberty. Without a history of the impact of mass vaccination, the procedure did look risky, and there were plenty of adverse outcomes to fuel antipathy to vaccination.

However, with the progress of medicine and the manifest success of public health measures overall, the rhetoric of the snake oil salesmen sounded less convincing while the frequency of adverse outcomes declined. The anti-vaccination movement disappeared in the first decade of the 20th century and science-based medicine and mass vaccination was generally accepted until the 1980s.

However, because of this hegemony, the medical establishment suffered from a measure of hubris. Critics of medical science began to appear in the 1960s, such as Critical Psychology which began among Psychology students and other critical trends within psychology, the natural childbirth movement also emerged *within* medicine; the Women's Health movement in the 1970s involved both medical professionals and patients demanding women have a say in how they were treated, culminating in the HIV/AIDS Movement in the 1980s. The AIDS activists objected to terminally ill people being given placebos in clinical trials, and demonstrated that research could be far more effective if people with AIDS were included as *collaborators* rather than objects of research, and that gay men, drug users and prostitutes were better placed to design and implement public health programs than public authorities, and the medical institutions were dragged kicking and screaming into collaboration with their clients.

A rising tide of voices objected to the abuse of research subjects, the marketing of drugs which later proved to be toxic, the corruption of GPs and researchers by companies, dangerous and unethical research practices by the military. Modern conditions contributed positively to the formation of these opposition projects but the scientific and medical institutions failed to rein in their hubris before these voices were raised. Among the critical voices were a number of anti-vaccination groups, which first appeared in the 1980s, after the decline of the 'new social movements' and in the wake of the AIDS controversy and the whooping cough scare.

According to Blume, these anti-vaccination groups are predominantly self-help groups of people who have become anti-vaccinationist as a result of their adverse experiences that they associate with vaccination. Their message is promoted over the internet and is easily accessible for anyone who goes looking for them. According to Blume, only 2% of parents consult the internet in making their vaccination decision, and only a proportion of these would even read an anti-vaccination website, let alone trust it. Only a minuscule proportion of the population would have direct contact with an anti-vaccination group, insufficient to explain the extent of vaccine hesitancy. So vaccine hesitancy is *not* the product of scaremongering by anti-vaccinationists. These groups do indeed propagate misinformation, but their influence is negligible. They are a *product* not a cause of widespread vaccine hesitancy.

The most dramatic collapses in the safety of specific vaccines have occurred in direct response to doubts raised *within medical research itself*. But parents did not get this information by reading the *Lancet*. They received the information mainly through conversations with friends, family and neighbours. A survey showed that 75% of parents who had made a decision on vaccination had had at least one discussion on its advisability with the relevant health professional and 85% had read the literature provided, but 16% felt they needed more information. For the majority it was the information they received from *trusted peers* which was most decisive in forming their

opinion. Moreover, the proportion of parents distrusting the information from health authorities is growing. This group is strongly correlated with people using 'alternative' therapies. However, Blume finds that active criticism of vaccination by advocates of alternative therapies is also insufficient to explain the decline in vaccination rates, although such views are finding increased sympathy among the population at large.

So the question is why increasing numbers of people are open to arguments that the medical establishment should not be trusted and accept advice which contradicts the scientific consensus. One bad experience sows the seeds of doubt, but this would not be enough for a parent to reject the advice of their doctor. Given that publishing by vaccine sceptics and alternative therapists is not in itself sufficient to explain the extent of vaccine hesitancy and its growth, it seems that it is when parents consult their trusted friends, neighbours and family that doubts become consolidated.

Blume claims that the best predictor of vaccine hesitancy is "a general commitment to holistic ideas about health (and to natural child birth and breast feeding) and the importance of life style and environment for a child's well-being."

Information about vaccination from the media, friends and neighbours, alternative health practitioners and health professionals will be framed by this pre-existing view. Most influential in developing this 'holistic' view of medical issues are friends and neighbours, not professionals of any kind. *Local* vaccination cultures form because it is through friends-and-neighbours networks that antivaccinationism is propagated, as an incidental part of interest in 'holistic medicine'. Generally speaking, the original source of a vaccine scare is *genuinely authoritative*, but it is hearing it from a trusted source which is decisive for its acceptance.

Vaccine hesitancy is not the product of an antivaccination social movement as such, but the by-product of a movement *for holistic health*. Science is a hegemonic ideal: the wackiest strand of alternative medicine still lays claim to science, even if without basis. In itself, an holistic health movement ought not to be a danger to public health. But because it arose as a critique of institutionalised scientific medicine, holistic medicine is saddled with a fatal contradiction – it excludes the only party capable of producing a genuinely holistic theory of well-being: scientific medicine.

The holistic medicine movement should recognise that they are in the same position as the HIV/AIDS Movement was in the mid-1980s, being treated as irrational pariahs by the institutions they need to collaborate with. The medical establishment needs to make the same realisation, instead of treating antivaccinationism as an irrational curse, they need to enter into a collaborative relationship with it as part of a scientific holistic medicine movement. This was the outcome of both the Women's Health Movement and the HIV/AIDS Movement.

Nowadays, people want to make the decisions about their own health and that of their children 'for themselves'. In fact such a decision is possible only by weighing up conflicting sources according to trust. The sources of information themselves – whether neighbours or professionals – and assessment of those sources, are constructed through participation in collaborative projects and generally speaking one trusts a collaborator before someone you have never collaborated with. If your doctor has only ever issued instructions, then you are unlikely to trust them. For many people the only collaborative relations they have are with family, colleagues, friends and neighbours.

The brochures provided by the health system supporting vaccination make no pretence at helping you make your *own* decision. They are transparently aimed at *persuading* you to comply.

The medical establishment is part of the problem and the holistic health movement is part of the solution. Only by these two projects collaborating can scientific medicine become genuinely holistic and the holistic health movement become genuinely scientific. Most people are unaware that the positivist, narrow and dogmatic style of

doing science and medicine is only *one style* of doing science. Science is, in essence, holistic and collaborative. But science also relies on trust; it needs to trust its sources, and the elaborate procedures by means of which science verifies its sources is the most essential part of the scientific project. You cannot claim to be holistic if you exclude the most significant source of experience, the scientific establishment. Medical experts have to be *engaged* and drawn into collaboration. People become doctors, public health officials or nurses, because they want a career in promoting health. The departmentalisation of all the relevant institutions militates against a holistic approach, but medicine is in essence holistic. In collaboration with non-experts who insist on taking the idea of holistic medicine seriously, these structural problems can be overcome. By participating in the necessary transformation of the health system, the holistic health movement would itself be transformed.

The vaccine hesitancy arising from the growing distrust of institutionalised medicine is a serious problem. If it continues to grow, we will eventually learn our lessons in the wake of a global pandemic. Otherwise public health authorities must take the holistic health movement seriously and engage them in finding practical solutions in collaboration with the medical profession. 'Representatives' of the holistic health movement are not easily identifiable, but people who may be influential in localities where there is an antivaccination culture, could be engaged in formal deliberative dialogue, not to persuade but to explore solutions.