

Immunisation policy: from compliance to concordance?

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SUMMARY

Immunisation has proved a highly effective public health policy. However, it has come under public suspicion at times, with large falls in pertussis immunisations in the 1980s and smaller falls in measles, mumps and rubella (MMR) vaccine uptake recently. Immunisation scares have also occurred in other countries.

This discussion paper explores the concepts of herd immunity, altruism, and informed consent. Historical, quantitative, and qualitative research on the sociology of immunisation is reviewed. Recent research has shown that the concerns of parents include a loss of trust in health professionals and increasing worries about side effects.

The sociologist Streefland is the leader of the World Health Organisation Sociology and Immunisation Project. His concept of the five perspectives on immunisation is explained. Concordance is then described as a dialogue based on mutual respect between different perspectives. Finally, some suggestions are made for immunisation policy in the UK.

Immunisation policy should move from the current situation, which largely assumes the passive compliance of the population, to a policy where people are actively involved and their views respected.

Keywords: immunisation; policy; sociology; compliance; concordance.

Introduction

MASS immunisation for protection from infectious disease is generally acknowledged to be one of the most outstanding achievements of modern medicine,¹ and its benefits have been eloquently set out.² However, it has recently come under public suspicion, with large sections of the population turning away from pertussis vaccination in the 1980s,³ and, more recently, from the triple measles, mumps and rubella (MMR) vaccination.⁴⁻⁶ The significant fall in coverage that led to a pertussis epidemic in the 1980s has not been repeated on the same scale for the MMR vaccine.⁷ Similarly, there has been resistance against hepatitis B vaccination in France, based on the belief that it causes multiple sclerosis.⁸ One campaign against it was so successful that routine immunisation of adolescents in France was suspended in 1997.⁹ While an older generation can remember the infectious diseases for which we now have vaccinations, there is a generation that has never seen measles, let alone polio or smallpox. There is a much greater public distrust of medications in general, and vaccines in particular, together with an increased awareness of side effects. In such a climate, it is proving difficult to maintain the high coverage needed for herd immunity. In the *BJGP*, Jewell suggests that it is time for a new approach to the public, to listen to the lay voice without an excessive dependence on experts.¹⁰ Shortly after this article was published, perhaps through coincidence, the Joint Committee on Vaccination and Immunisation of the Department of Health in England agreed to appoint a lay member. This appointment has, however, so far been delayed.¹¹ Can we, then, engage the public in decisions about vaccination, paralleling the advocated move from compliance to concordance with regard to medication?^{12,13} Are the taking of medicine and the acceptance of immunisation sufficiently similar for this to be a useful analogy (Table 1)? Can research tell us anything about how those who refuse immunisations think, and therefore how we might talk to them?

The developing world

First through the Expanded Programme on Immunisation (EPI), and more recently through the Global Alliance for Vaccines and Immunisations (GAVI),¹⁶ vaccination has proved to be dramatically effective in developing countries. Immunisation has lowered rates of childhood mortality there, especially against measles. This effect has been seen even where living standards are falling. This is in contrast to the developed world, in which McKeown¹⁷ demonstrated long ago (although some would qualify this),¹⁸ that declining mortality preceded immunisations and was owing to other factors, such as public health improvements and rising living standards. However, even in developing countries there has

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been resistance against vaccination. For example, in the Philippines a rumour arose that tetanus toxoid vaccination was being used for family planning purposes. For this reason, it was strongly opposed by the pro-life Roman Catholic Church. The Church was able to obtain a court order forbidding the Department of Health to continue giving the vaccination.^{19,20}

Herd immunity, altruism and consent

The effectiveness of immunisation depends on two factors: personal immunity leading to some protection against infection, and herd immunity, which prevents the infectious agent from circulating in the community and which protects both the immunised and those who are not immunised. The decision to immunise a child may therefore have an altruistic element; that is to say, there is an intention to benefit not only the child, but also the whole community.²¹ This altruistic element will be particularly marked for some vaccines and absent for some, such as the tetanus vaccine. For example, in the early days of pertussis vaccination in the United Kingdom (UK), children who were older than six months were vaccinated, yet the principal beneficiaries of herd immunity were children from birth to six months of age. These young babies were the ones who were most at risk from pertussis. In another striking example in Japan, vaccinating schoolchildren against influenza was obligatory from 1977 to 1987. This was principally to provide indirect protection against influenza to elderly adults.²² This altruistic element is of direct relevance to informed consent because, unless the parents are aware of it, their consent is not informed. Valid consent requires a sound mind, sufficient understanding, and a free agreement.²³ There has been particular emphasis on consent in the United States, and more recently in the UK.²⁴ The importance of this altruistic element is clear, because the damage to the community is rapid and obvious if immunisation rates fall. In the UK in 1974, for example, a report on the adverse effects of pertussis vaccine was taken up by the media.²⁵ This led to a fall in vaccine uptake to 30%, and then an epidemic of pertussis. It took a decade for immunisation uptake to return to previous levels.³

The scope of research to date

In summarising research to date, it is important to be aware of both the variety of research methods used and the very different groups of people who do not accept immunisation among whom this research has been carried out. A non-systematic search reveals data in many places, mainly social science databases, with only a minority indexed in MEDLINE. Techniques range from narrative-based methods

(including historical research),²⁶⁻³² to qualitative³³⁻³⁸ and quantitative methods,³⁹⁻⁴² and, lastly, epidemiology.^{3,9}

The subjects in the groups interviewed range from those who refuse all immunisations⁴³ to those who accept only some,^{3,9,19,20,33-35} and, lastly, to those who accept the full immunisation programme.³⁸ There is a particular shortage of qualitative research into the last group, therefore there is scope for research on why parents who have their children fully immunised choose to do so. Finally, the researchers set out to find very diverse reasons for refusal to immunise. Some researchers were looking for group reasons for refusal,^{9,19,20,43,46} others for individual reasons,^{33-37,43} and others were looking for difficulties of access owing to geographical factors, transport, or staff rudeness.⁴⁴

Research in the UK

Early research into vaccine coverage emphasised social and cultural factors, such as class and employment.^{39,40,45} Qualitative research in the UK into what people think about immunisation is sparse. An early qualitative paper showed that those people who did not immunise did not differ as much from those who did so in relation to access to immunisation as in their beliefs about immunisation.³³ In the 1980s, Rogers and Pilgrim^{34,46} conducted a number of interviews with parents and professional groups. They emphasised that those who were against immunisation had a rational position, albeit that it was different from the official one. They noted that: 'this group of mothers tended to be paragons of virtue, if not zealots, about reducing potential risks to their children's health in every respect except immunisation'. They also felt that the official view minimised or glossed over the possible side effects of vaccines. These conclusions were criticised in other papers in the same symposium as Rogers and Pilgrim. These papers emphasised the safety of vaccines, the severity of some infectious diseases, and the lack of evidence of long-term harm from vaccines.⁴⁷

Two UK papers have looked at this area recently. The first was a focus group study with groups of both immunisers and non-immunisers.³⁸ This study, which was among the first to concentrate on immunisers, showed that they shared the concerns of non-immunisers. Non-immunisers were more likely to be concerned about unknown long-term side effects of vaccines and to consider that vaccines placed stress on the immune system, rather than strengthening it.³⁶ The other UK study was of non-immunising parents.³⁵ In both studies the risk of side effects was found to be an important issue for the parents. They discussed immunisation from a risk perspective, and had lost trust in health professionals. For these parents the decision about immu-

Table 1. Differences between immunisation and the taking of medicine.

	Immunisation	Taking of medicine
Public act	Yes	No
Single or continuous action	Mostly single	Continuous
Potential effect of decision on other community members	++	+
Legitimate public interest	+++	+
Altruistic component to action	Often	Slight
Typical level of full acceptance/compliance (%)	≥80	50 ^{14,15}

nisation was an ongoing process, not a single decision.³⁷ While immunisers felt that it would be their responsibility if their child developed an illness owing to their failure to immunise, non-immunising parents took the opposite perspective. They would have felt guilty if their child had side effects, but if their child fell ill, this was seen as natural and not their responsibility.^{34,38,48}

Research worldwide

There has been an organised effort by the WHO, through their social science and immunisation project, to obtain data from developed and developing countries.^{49,50} The results have been summarised by Streefland.^{8,44} The causes of failure to immunise have been found to differ in developed and developing countries.⁸ In developing countries non-immunisers may find access difficult, they may have had experience of rudeness from people working in immunisation services, or they may belong to a social group whose ideology clashes with that of the government promoting the immunisation programme.⁵¹ In developed countries resistance may be owing to an organised belief system, such as homeopathy,⁵² Christian Science,⁴³ or anthroposophy,⁵³ but more typically it is on an individual basis, as a personal choice. Where there is individual choice, however, it may be informed by various sources. As well as the popular press and books, there is a plethora of websites that are violently against immunisation.⁵⁴⁻⁵⁷ In an excellent paper, which summarises work to date on the sociology of immunisation, Streefland describes five explanatory perspectives on immunisation⁴⁴ (Box 1). Each perspective could be seen as a separate discourse; that is, a scheme of mutually cohesive and related ideas. Any individual is likely to view the situation from more than one perspective or participate in more than one discourse.

One perspective is that of normality. For example, there is the case of the mother who has her child immunised because it is the 'normal' thing to do, and it is what her friends do. Identity is defined by the choices we make, as described by Anthony Giddens.⁶⁰ This perspective is that of the well-educated non-immunisers interviewed by Rogers and Pilgrim.⁴⁶ It contrasts with pre-modern societies, where the group to which one belongs more closely defines the choices that are made. However, social factors still have strong effects in modern societies,⁶¹ and indeed they have recently been shown to influence MMR coverage.⁶²

For the mother using the 'rational choice' perspective, the question of trust becomes important. Which source of information should she trust? Falling trust in experts is a recurring theme in modern society.⁶³ In the case of immunisation there is the particular problem that general practitioners (GPs) no longer give unbiased advice. Since the 1990 Contract, they are paid by the National Health Service to give the advice reckoned to be of greatest good to the community. Initially, paying GPs to reach certain targets by improving their organisation and the advice they gave had dramatic results in improving immunisation coverage in the UK, although a Cochrane review of target payments worldwide shows only a small effect.⁶⁴ Some research suggests that non-immunising mothers are now discounting their GPs' advice because they believe it is biased by their finan-

cial stake in the process.^{35,38} If this is the case, then we should reconsider this method of payment.

How to improve coverage

Are there any other ways to improve coverage? Recent publications include an editorial in the *BJGP*,⁶⁵ a Cochrane review showing the effectiveness of patient reminders,⁶⁶ and a meta-analysis of interventions to improve immunisation.⁶⁷ These have shown that, after health service factors, financial incentives and reminders to mothers are the most effective interventions. Incentives to the mother have not been tried in the UK, but have been tried elsewhere. Proof of immunisation has been required for school entry in the United States (US), some parts of Germany, and some states in Australia. In France, proof of immunisation has been a prerequisite for receiving certain benefits.⁴⁶

What might we mean by concordance?

Concordance in immunisation policy must mean a process that occurs not only at the individual level, but also at a societal level. Concordance needs to be more than just a transfer of information about consumers' wishes to the state; it must involve a transfer of power to some degree. Simply improving presentation by means of techniques such as focus groups to elicit opinion may improve coverage in the short term, but could be seen in the longer term as coercing the public and could further alienate them. This potential danger of the abuse of qualitative methods has recently been pointed out.⁶⁸ Concordance in immunisation policy is a specific example of the question of involving the public in healthcare decisions. According to Holm, we can only hope to make this process transparent, accountable, and fair.⁶⁹ We cannot hope to make it fully rational because the goals of a healthcare system are multiple and indistinct. The problem with immunisation is how to capture the multiple explanatory discourses used by the parties involved, especially the mothers, and make them mutually comprehensible.^{70,71} This does not necessarily mean something 'warm and cosy'. For example, if the day came when most mothers thought of immunisation in terms of risk analysis, then the current successful policy of immunising baby boys against rubella would become untenable because there is little benefit to the individual boy.

Concordance must mean more than evidence-based health care⁷² simplistically interpreted. Those who pioneered evidence-based medicine emphasised from the beginning that the evidence should be applied to the individual.⁷³ However, some of those who followed their lead have not taken into account the fact that many people look at life quite happily from a number of different perspectives. For example, they may have both a scientific view of the world and other quite incompatible world views. Concordance, then, should mean not only applying the evidence to the individual, but also dialogue between perspectives based on different views of the world. It means an exchange of views and mutual respect between these very different views. Certainly, this can be difficult. For example, the recent report of the Chief Medical Officer's working party on chronic fatigue syndrome and myalgic

Explanatory perspectives	Name of perspective	Whose perspective	Example
The perspective of variation in rational vaccine use		Parents as members of a culture, medical anthropologists	'We Tumbuka people believe needles strengthen our children'
The perspective of collective decision by vaccination users	Normality	Parents as members of a group	We have our children immunised 'because it is the normal thing to do'
The perspective of trust in the competent provider	Trust	Individual mother	'I have my child immunised because I trust the advice of this professional, whom I know'
The perspective of risk perception	Rational choice	Individual mother	'I make a rational decision and I choose for my child on the basis of my perception of the risks and benefits'
The perspective of state, power, and the body		Policy makers, epidemiologists, etc.	'The protection individuals gain from herd immunity is greater than individual immunity and therefore it is society's responsibility to ensure that children are immunised'

Box 1. Streefland's five perspectives explaining differences in immunisation coverage.⁴⁷

encephalomyelitis⁷⁴ demonstrated an attempt to synthesise disparate voices, but failed to keep the original broad-based membership together.

That it may be possible is, however, at least suggested by an interesting new approach pioneered by Professor Jake Chapman, working with large organisations.⁷⁵ He maintains that large organisations — and the immunisation system could be viewed as one of these — are not simple linear systems that can be managed by a command and control style of management. Each of these is a complex adaptive system whose whole is, in some sense, greater than the sum of its parts. His approach, which has been successful with large government information technology projects,⁷⁶ involves finding solutions to which all participants subscribe, showing sensitivity to different perspectives, and avoiding multiple pre-set targets that can have perverse effects.

Conclusion

There have been protests against immunisation from the earliest days of smallpox vaccinations.^{26-29,31} In a free society it has proved necessary to allow for conscientious objection and to accept less than 100% coverage. However, in this current post-modern society, the 'top-down' policy currently pursued by the Department of Health is, in the opinion of many, likely to work less and less well. We will need to engage with the public concerning the need for immunisation, perhaps by means of focus groups to elicit public opinion and go beyond the public surveys currently carried out.⁷⁷ We will need better public information campaigns. Some videos already exist, and these could be more widely disseminated.⁷⁸⁻⁸⁰ Perhaps the government's new health promotion agency will be the right agency to organise this.⁸¹ There needs to be a shift in immunisation practice, parallel to that regarding the taking of medicines, from compliance to concordance. Such a change requires ongoing qualitative research into how both immunisers and non-immunisers think. It will require much greater funds for public information campaigns when new immunisations are decided upon. However, such changes are needed if the benefits of this old and established public health practice are to be maintained

in the new millennium. It could be said that public policy about immunisation illustrates and reflects a current tension in wider health policy between an increased reliance on scientific evidence and a wish to have a patient-centred approach, and between the needs as defined by the experts and the wants expressed by the public.

The latest change in the UK immunisation policy against diphtheria is a good example of the current approach. Recently there have been epidemics of diphtheria in the countries of the old Soviet Union. Surveys have shown that the adult population of the UK have little protection against diphtheria.⁸² The response of the Department of Health has been to write to vaccine manufacturers in the UK discouraging them from producing single antigen tetanus vaccine. Soon, only double antigen tetanus and diphtheria vaccines will be available. A circular has been sent to GPs and accident and emergency departments informing them of this change.⁸² There has been no consultation or attempt to inform the public, and it will be left to GPs and others to inform patients of the need for vaccination when they attend with minor injuries. This approach is open to the risk that another anti-vaccine movement will arise, demanding single tetanus vaccine. A new approach that elicited public opinion, allowed for conscientious objection, involved the target groups in decision making, and included a public information campaign that created a social demand for immunisation,^{44,51,83} would reduce these risks.

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