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, and its benefits have been eloquently set out. However, it has recently come under public suspicion, with large sections of the population turning away from pertussis vaccination in the 1980s, and, more recently, from the triple measles, mumps and rubella (MMR) vaccination. 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. Similarly, there has been resistance against hepatitis B vaccination in France, based on the belief that it causes multiple sclerosis. One campaign against it was so successful that routine immunisation of adolescents in France was suspended in 1997. 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. 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. Can we, then, engage the public in decisions about vaccination, paralleling the advocated move from compliance to concordance with regard to medication? Are the taking of medicine and the acceptance of immunisation sufficiently similar for this to be a useful analogy? 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), 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 McKeown demonstrated long ago (although some would qualify this), 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
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.26

**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 a 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,5,19,20,43,45 others for individual reasons,35-37,43 and others were looking for difficulties of access owing to geographical factors, transport, or staff rudeness.34

**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 Pilgrim34,46 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

| Table 1. Differences between immunisation and the taking of medicine. |
|-----------------|-----------------|
| **Immunisation** | **Taking of medicine** |
| Public act       |                  |
| Single or continuous action | Yes | No |
| Potential effect of decision on other community members | Mostly single | Continuous |
| Legitimate public interest | + + + | + |
| Altruistic component to action | Often | Slight |
| Typical level of full acceptance/compliance (%) | ≥80 | 50 |

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nisation was an ongoing process, not a single decision. 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.

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. The results have been summarised by Streefland. The causes of failure to immunise have been found to differ in developed and developing countries. 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. In developed countries resistance may be owing to an organised belief system, such as homeopathy, Christian Science, or anthroposophy, 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 informed by various sources. As well as the popular press and books, there is a plethora of websites that are violently

Discussion papers

How to improve coverage

Are there any other ways to improve coverage? Recent publications include an editorial in the BJGP, a Cochrane review showing the effectiveness of patient reminders, and a meta-analysis of interventions to improve immunisation. 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.

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. 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. 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. 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 care simply interpreted. Those who pioneered evidence-based medicine emphasised from the beginning that the evidence should be applied to the individual. 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
encephalomyelitis 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. 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, 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. 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. We will need better public information campaigns. Some videos already exist, and these could be more widely disseminated. Perhaps the government’s new health promotion agency will be the right agency to organise this.

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. 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. 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 antigen vaccines. 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, would reduce these risks.

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