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## **Childhood immunisation: meeting targets yet respecting consent**

### **Abstract**

In England and Wales, general practitioners receive extra payments when they meet set targets, that certain percentages of their youngest patients are immunised. Fifty eight primary health care practitioners were interviewed about their views on childhood immunisation, and how targets with financial incentives might affect parents' choice about immunisation. They were asked about two responsibilities which can potentially be in conflict: to increase rates of childhood immunisation, yet also to respect parents' voluntary choice about whether their child is immunised. Professionals' reported uncertainties and disagreements are described, and the view that these can be resolved through training in communication skills is discussed.

### **Key words**

childhood immunisation, consent, risk, communication skills

### **Introduction**

Childhood immunisation in the UK is voluntary. In order to increase immunisation rates, the government has set targets for general practitioners to meet if they are to receive extra payments. In 1992 the targets were 90% uptake for all vaccines by the second birthday. By 1995, it is hoped that targets of 95% will be met.<sup>i,ii</sup> This policy raises the question: What do primary health care practitioners think about the contradictions between policies to increase rates of childhood immunisation, yet also respect parents' voluntary choice about whether their child is immunised? During 1993-94, a qualitative research project commissioned by the Health Education Authority investigated professionals' views on this question. Records from the end of 1987-88 of children born in 1985, and from the end of 1993-4 of children born in 1991-92, showed that rates rose from 87% to 95% (diphtheria, tetanus and polio), 73% to 93% (pertussis), and from 76% (measles) to 91% (measles mumps and rubella).<sup>iii</sup> The steady rise began before targets were introduced so that their actual effect on practice is not clear.

### **Methods**

Tape-recorded, semi-structured interviews lasting 45 to 60 minutes and based on a question schedule were held with 58 primary care practitioners. The questions covered practitioners' professional and personal experience of childhood immunisation, their views on consent, their responses to parents' questions, dissent and default, their views on the politics of childhood immunisation and their training needs. Questioning methods included requests for yes/no replies, for qualified responses, the selection of one or of several responses from a list of options, and accounts of complex views and examples of typical or unusual encounters with parents. Interviewers were recruited for their skill in qualitative research and knowledge of immunisation and the research team met for two half-day training sessions. Data were analysed by an spss.pc

computer programme to give a background indication, for example, of whether a concern was commonly or rarely held; qualitative data were selectively transcribed and analysed by hand. The purpose of the study was not to measure frequencies or to examine actual practices, but to conduct a qualitative exploratory study of practitioners' views of links between parents' consent and immunisation rates. The complex replies are conveyed more fully through quotes than through tables.<sup>iv</sup> Question design was aided by review of the literature on childhood immunisation and on parents' consent to health care interventions.<sup>v</sup>

### **Respondents**

Interviews were held in three types of areas: inner city, suburban and semi-rural. A convenience sample of practitioners was selected to obtain a reasonable balance of the four main professions. The 58 respondents were 18 General Practitioners (GPs), nine Community Medical Officers (CMOs), 16 Health Visitors (HVs), 12 Practice Nurses (PNs), a doctor working in management, a practice manager and a minority group's advocate. There were 11 refusals mainly by GPs in small practices, and suburban CMOs, on grounds of lack of time. Interviewees probably had an above average interest in immunisation. There were 43 women, and the 15 men were all doctors. The respondents had worked in the field of childhood immunisation for a mean time of 7.8 years, with a range from 30 to less than one year. Most of them thought that experience had not altered their views about parents or consent, although some thought that over the years they had acquired more respect for parents and more concern for parents' consent.

### **Practitioners' views of parents' reports**

As concern for consent tends to increase with higher risk medical procedures, we asked for professionals' views of parents' perceptions of risk: how often did they find that parents reported physical changes in their baby shortly after immunisation, and how accurate did practitioners believe the reports to be. Nearly two thirds thought that parents seldom reported changes, though 16 replied 'quite often', and 4 said 'very often'. Whilst 30 professionals believed that parents' reports of possible links between immunisation and subsequent physical changes in the baby were generally accurate, 15 thought that parents tend to over-estimate such links, and 2 thought that parents under-estimated them. Professionals' concerns about parents' reports ranged from 'not worried' (38), to 'quite worried' (12), and 'very concerned' (1). Professionals' views were coloured by their own experiences, of seeing children who were either very ill with the diseases that could be prevented, or with apparent effects from immunisation. A GP commented, 'My own child had a spectacular, severe reaction to the first pertussis, and developed eczema, so that vaccine wasn't repeated, and I sympathise with parents who want to omit it. But if they are worried, I do jolly them along'.

### **Dealing with reservations, dissent and default**

Parents' responses to professionals' advice to immunise babies were reported to range:

from respectful acceptance (most usual in the rural area, 'It's just accepted, everyone does it, like sheep, they don't really think about it');

to default or non-cooperation (mainly in the inner city through parents being

`disorganised', often moving home, or not speaking English as a first language); to questioning and, in some cases, dissent (mainly in the suburbs among well-educated parents).

Some professionals respected parents' objections as carefully considered, even if they disagreed with them, as other studies confirm.<sup>vi</sup> Others dismissed parents' views as ignorant or as selfish. `Even if their child will be all right, it increases the risk for other children, especially less fortunate ones'. When asked to select the word fitting their predominant view of parents' responses, they selected `generally sensible' (13), `ignorant' (8), `confused' (5), `sometimes sensible' (5), `irresponsible' (1), `selfish' (1), and others said that parents varied. Selecting one or more terms from a list of parents' objections that they most often encountered, interviewees selected `there might be specific harm to the particular child' (45), `immunisation might generally harm the child' (26), `timing is too early/too inconvenient' (6), `parents feel too uncertain or too uninformed' (5), `cultural/religious objections' (4), `general good but at possible cost to individuals' (1). On how best to respond to parents' objections, many professionals argued for more than one type of response: `give them detailed oral information' (42), `encourage them to accept immunisations' (37), `reassure them that immunisation is safe' (27), `respect their views' (26), `listen to them' (24), `tell them it is their decision' (23), `give them written information' (19), `give them time to think' (15), `try to overcome their resistance' (13). While often seeking to reassure and encourage, some respondents stressed the need to inform, to listen, and to respect parents' views. On a personal note, most of the 42 interviewees who were also parents had had their own children immunised, but 5 in this sub-group were sufficiently concerned to decide against their children having the full range of antigens.

### **Government and professional policies**

We enquired: How far and in what ways do government policy interventions, such as targets, guidelines and advice, and financial arrangements influence professionals? Only 22 respondents thought that 2-5 months is the optimal timing clinically for the first immunisations; 40 thought the timing was advised for convenience while many mothers still attended clinics.

Only 27 professionals believed that government policy affected take-up rates, and 15 thought that the policy worsened their relations with parents. The question `Do professionals sometimes feel expected to carry out government policy?' elicited the highest agreement rate of all the replies; 48 replied `yes'. Many complained of increasing amounts of paper work. One GP said: `I feel very angry about targets. My relationship with patients is becoming increasingly damaged. I think, increasingly, things like coercive consent will become a problem; they'll see me more as a policemen, not a doctor, and they're going to start complaining about everything I do and lower my morale'. Another GP said, `Much as I loathe the new contracts I do feel that the targets have encouraged uptake'.

Over one third (23) of respondents said that at times they experienced a conflict between duty to the child (such as to give the protection of immunisation) and respect for the parent (in a case of refusal). A CMO remarked: `A lot of parents see their children as goods and chattels. They don't appreciate that their child, if they were mature enough to speak, might say, "But mum, I don't want to catch whooping cough". One HV said: `It is the first decision they have to make as a parent when they can't be

their child's best friend. No one likes sticking needles into babies'. A CMO remarked: 'When you become a mother yourself, you realise much more the responsibility and the difficulty of making a decision; if anything goes wrong, it's your fault'. Twenty two professionals experienced conflict between duty to an individual child (such as whether to immunise a child who is possibly at higher risk) and to the child population (to increase general immunity).

## **Consent**

Professionals were asked for their views on three requirements for consent to children's health treatment: that consent means an informed, uncoerced, voluntary choice, and a wise decision in the child's best interests.

### Consent as an informed choice

Although 34 said that they thought they could give reasonable amounts of information to most parents, two-thirds of professionals described constraints on giving information: 16 said 'lack of time, 6 said 'lack of knowledge', some felt under pressure from colleagues not to give full information, or were reluctant to raise parents' anxiety. Most professionals thought that they overcome constraints, or that parents appeared satisfied or 'made a good decision'.

Informed consent means understanding the nature and purpose of the procedure, the risks, benefits and any alternatives.<sup>vii,viii</sup> However, among the respondents, information was limited by uncertainty about risk and legal liability, and by disagreement among the primary care team. One HV said: 'I definitely think the PN who gives the vaccinations needs updating. She doesn't like giving them when a child is slightly unwell but it is not contraindicated. I would support her in that, she shouldn't have to do anything unless she's happy. She won't do opportunistic vaccinations because she doesn't think she's covered and that causes a lot of confusion. I think these conflicts are the most difficult part of immunisation. We're all supposed to be working together. But it doesn't seem right for GPs to put pressure on parents because they're going to be paid.'

'Risk' was variously described. Comments on probability, such as 'the risk is very slight, very rare', implied a risk of mortality or severe neurological damage. Some people denied that immunisations could cause such damage. Others were concerned about common minor reactions, fever, swelling, and prolonged crying, which could greatly distress babies and their parents; others thought that many of these reactions were due to other reasons: 'they're always having colds at that age'. No one knew the likely incidence of the degrees of morbidity associated with each serum, or the exact means of identifying contra-indications in all relevant cases, so that consent could not be based on clear risk-benefit evaluation.

With non-English speaking parents, an advocacy service coordinator was concerned about over-immunisation in families who moved home frequently, whose records were incomplete or where the baby had already been immunised abroad. She felt that an advantage of the targets was that more advocates were being employed to improve rates and that this improved communication between families and professionals. 'If people refuse, there must be a reason for it. You need to get to the root of the problem, listen to them, it's about trust... It's important to make them feel they can ask questions without looking stupid. Consent means choice'. One CMO said: 'Well informed consent is based on a thorough discussion of the issues'. A PN believed:

`The main thing is to give them the choice. As long as they know the pros and cons, the final decision is theirs. Some people ask more questions, and perhaps they're more educated. The parent is the child's guardian, it is their right'. The main dissenters were educated middle-class mothers influenced by homeopathy and beliefs that immunisation might undermine auto-immunity.

Notions of `reasonable' amounts of information varied. One GP said, `I don't offer information if I'm not asked. If you go jabbering on ... people get apprehensive. I go blindly on. I've never seen a serious reaction of any kind. I believe in immunisation, so the parents automatically do'. Another GP said, `Informed consent isn't an issue. It used to be when there were scares about pertussis but now it's fairly rare for people to want you to go into great depth'. A third GP said that consent only applied with major interventions.

Others preferred to give more detail, such as the HV who commented: `We need to educate parents by discussion, not coercion, and by giving literature to reinforce what we say, with hard up-to-date facts'. Some HVs left the GP to give information, `He's paid to do that, I'm not', but others felt tensions between informing parents more fully, but also `being an employee of the Trust, I'm bound to follow the policy of advocating immunisation for children'. PNs who are directly employed by GPs could feel obliged to carry out GPs' instructions even if they thought that parents had little or no information. Only 12 of respondents said that their practice or clinic had an agreed procedure for obtaining informed consent; 12 saw little need for an agreed process, 8 said that `people need individual approaches', 29 said that they `volunteer information to everyone' and 8 that `we only inform parents who ask'. However, 30 thought that parents generally understand and 20 thought that they `partly do'.

#### Consent as a wise choice

Do the professionals think that most parents make wise choices about immunisation in their child's best interests? Over one third said `yes, whatever the parent decides', and 20 thought that parents are wise only if they agree with professionals. Yet 45 thought that the decision to immunise should not rest with professionals. Discussing wise and informed decisions, a GP remarked: `It's a benefit/risk assessment. They make a decision for perfectly valid reasons. Valid doesn't necessarily mean scientifically correct... you really have to have thought your reasons out... It would be wrong if professionals ultimately decided. You come to me for advice, for a consultation, not a dictation'. Another GP said: `If they have anxieties about pertussis, and they don't take it up, I think it's wise, because they've thought about it and they're good, thoughtful parents. We very definitely don't have the right to take ultimate responsibility for deciding about immunisation. Cor blimey, - 1984 and all that'. (He referred to Orwell's novel about total state dictatorship.)

#### Consent as an uncoerced, freely made decision

Some professionals used the oxymoron `coerced consent'. One HV replied: `Consent is about compliance, we need to do more work on how to get them to comply, to take it up'. Some professionals used indirect pressure, such as the HV who commented: `When they're not sure, I say it's their choice, but I ask how they'd cope if their baby got whooping cough. Most feel they wouldn't be able to manage. I always give them plenty of time'. Others were more direct, such as the GP who said; `My duty is to the child, and not to have the child immunised because of grandmother's prejudice is unacceptable as far as I'm concerned. We don't get parents to sign. I sign over the

stamp we have. When new parents join, we have all the immunisation forms given to us, and we won't register a child without them. If parents refuse that will sway us against having the child on the list. If a child comes in and I notice the child hasn't had them, I sometimes will do them opportunistically. I think targets have improved rates. There's no doubt that money talks, and it's meant a lot of GPs have got themselves sorted out'. Other professionals described GPs telling parents to register with another GP unless the child was vaccinated, or refusing to register these children. Some thought that this was a disadvantage of the target system of payment.

#### Consent as a formally signified decision

In the UK, patients or parents are asked to sign consent forms before major procedures. Consent forms are used for immunisation in some districts, but not in others. There was confusion between 'intent forms' signed when the baby is a few days old and 'consent forms' signed at the time of the first immunisation. In the UK blanket consent in advance is not legally valid, consent should be requested for each procedure at the time.<sup>ix</sup> One PN said: 'Consent is the big issue. We did discuss written consent, but the doctors say they give implied consent, so we've never pushed the issue. I didn't at first feel happy, and whenever I go on a course and a lawyer talks I come back and say, "We must have written consent," but it wears off'.

Several professionals, in areas where consent forms were not used, described implied consent. One HV said: 'Parents give consent for the child by bringing it. We go by intent rather than a consent form'. One GP said: 'The ultimate is when they turn up to a baby immunisation clinic and proffer the baby's bum or arm to be injected. They have the option to refuse, not turn up, ignore it'.

The assumption that attendance implies consent is questionable when parents attend for other reasons, such as for a health check or to seek information. Some professionals who had greatest confidence in implied consent were also most keen on 'opportunistic' immunisation, even on home visits when the indications of implied consent least apply. Parents may be unaware, unprepared, possibly unwilling and occasionally carried along with the momentum of professional activity without feeling able to state their views. Professionals generally ignored discrepancies of power, authority and expertise between them and the parents. One said, 'We sit opposite at this table to show that we are equal'. However, the interviewer noted, 'I felt bull-dozed by this GP and wondered how parents felt'.

#### The value of discussion and consent

Nearly half the professionals (27) thought that informed consent had beneficial effects for parents, children and parent-professional relationships. However, 11 saw little effect, and 2 saw a generally harmful effect. All interviewees, at some time, had disagreed with certain parents' views. On discussions about immunisation with parents, 13 felt this was a valuable opportunity for health education, and 24 as valuable exchange of information when they could learn from parents. For one person discussions were 'rather a waste of time', but for 13 discussions were a worthwhile way to respect parents, and to establish good relations and a partnership of care for the baby. One GP said: 'Even if the child doesn't have immunisation, that discussion can be a solid rock for the doctor-patient relationship to build on: if you invest time it pays off in the long-term'.

#### Consent and compulsory immunisation

No one thought that professionals should have a formal right to decide, though 8 gave

qualified replies, such as the belief that they should strongly influence the decision. A few thought that the state should make immunisation compulsory but with proper compensation in cases of severe harm. The difficulties of assessing and attributing possible harm were discussed. One GP said: 'They've read some scare story in the Sun [newspaper]. It's these watchdog [television] programmes that cause problems. That makes life very difficult for us because obviously you don't want conflict but you want to protect the child and the community. If they still refuse it boils down to emotion at the end of the day, it's not logic. Rather than compel the patient to have it, it would be nice if it was government policy that every child entering school would have a certificate saying that their vaccinations were up to date... But it would have to be backed up by a genuine policy of giving help to patients who have problems, compensation should be automatic... Without very good evidence that you are going to damage a child, then that child ought to have the vaccine for the good of the community'. Another GP agreed: 'Consent is given by someone of sound mind who understands the issues being explained to them. But consent can be a source of anxiety, it's a great responsibility. It makes me wonder about the French system of routine immunisation without needing to ask for consent'. Others thought the decision should be made by parents, since they carry final responsibility for the child.

### **Training**

Twenty two professionals said they had no training about immunisation, and 16 said that their colleagues had not been trained. However, 30 of professionals said that they coped 'very well' with immunisation work and 22 coped 'fairly well', only one person reported a sense of failure. Although 34 said they thought that training would be helpful to them personally and to their colleagues, there was little interest in attending training sessions. This was attributed to lack of time or the belief that training on other issues would be more worthwhile, such as general aspects of child health, relations with parents, and training in 'communication skills' was frequently mentioned as valuable.

**In summary:** Their comments indicate that the professionals widely disagreed on, and that some misunderstood, the meaning of consent. A few urged compulsion; some professionals took account of knowledge, wisdom, responsibility and non-coercion as components of informed consent. Respondents described how they coped with uncertainties and tried to balance conflicting values. These commonly shared concerns included:

- lack of time, in busy noisy clinics, to talk with parents;
- lack of clear, sufficiently detailed leaflets for parents;
- language barriers;
- having to spend more time on immunisation, as a result of targets, and less on other tasks;
- uncertainty about how much to attend to parents' other concerns if this might mean deferring or cancelling immunisation;
- anxiety that disagreement over immunisation would deter parents from seeking further health care for their child;
- uncertainty about the benefits of new earlier timing for immunisations (2-15 months), and about regular changes in immunisation policies and timing;

uncertainty about contra-indications, about the slight yet very serious risk of anaphylaxis, the safety of each antigen, their possible adverse effects, and the means of preventing and treating 'minor' adverse reactions;

difficulties in assessing risk and benefit in preventive treatment of healthy children.

Political uncertainties included:

how to respect parents' rights, and babies' individual and collective interests when these seemed to conflict;

how fully to inform parents about the risks of giving and of withholding antigens, and to respect parents' anxieties;

worry about legal liability;

how much discussion, persuasion or threat to use to influence parents' decisions and to risk undermining good relations with parents;

how far to intrude on family privacy and on civil liberties, such as through giving opportunistic immunisations;

how far to allow political and financial considerations to influence clinical judgement;

how much each practitioner is an autonomous moral agent, or is answerable to senior staff and employers.

## Discussion

Interviews took place within the, sometimes severe, time-constraints of the respondents' daily work. As with all interviews, we do not know how representative the responses are. HVs and PNs tended to be more concerned about parents' views and reservations than GPs were, though the GPs varied. We are wary of generalising from the small sample, though uncertainty and disagreement about childhood immunisation are likely to be wide-spread.

The immunisation of young children raises unique problems, including the question: What sort of society do we want? There are no simple answers to the uncertainties listed above; professionals tended to establish individual positions so that some disagreed with their colleagues. Some professionals appeared to feel obliged to convey greater certainty and confidence than they felt. It could help professionals and parents if the conflicting values integral to childhood immunisation were more openly acknowledged.

Professionals discussed how they coped with sharing knowledge and control over decisions and, usually implicitly, what power they exercised. There appeared to be more concern about professionals' authority and parents' rights in the UK than, for example, there is in Sweden.<sup>x</sup> Professionals can coerce if they present their expertise as standards parents must accede to. The health staff tended to perceive mothers' understanding as irrational and emotional, but their own understanding as rational, factual and unemotional. This common view<sup>xi</sup> lessens the chance of mutual respect between health staff and parents.

Yet in immunisation decisions, the dissenters among parents are often well educated. This raises questions about the usefulness of educating people, if you want high take-up rates. Respect for informed consent means informing people, but this could decrease take-up rates. Informed consent depends on professionals giving information based on research and their experience. Yet their experiences can be limited. Usually, only mothers see every stage of the immunisation process. HVs may make initial contacts, PNs may do the immunisation itself, doctors may see difficult

cases and after-effects. The professionals' view will continue to be partial, until systematic prospective assessments are carried out with the help of mothers. However, there have been few studies of both parental and professional understandings of their own views and of each others' views, or of interactions between the two groups, regarding immunisation.<sup>xii</sup>

### Communication skills

Greatest concern was expressed by the interviewees about parents who believed that the risks of immunisation are high, or exceed the benefits. Many professionals thought that training in communication skills would help them, with these cases, sometimes to persuade people to do what they might not otherwise choose. Ostensibly, the skills are intended to improve clear information, listening, and shared decision-making, yet rates might decrease if parents are told more about risks and current uncertainties.

The phrase 'communication skills' tends to denote technique rather than content of discussion, though in cases of strong disagreement, improved skills may have little impact on the outcome. Techniques alone, such as reflecting or summarising, are unlikely to be used by practitioners who have little interest in their clients' views, who feel pressed for time, or whose main concern is to inform and treat patients. Techniques which aid communication are more than a veneer of behaviours, and express real respect and concern. Professionals who respect their clients are willing to believe that their own knowledge may be provisional, that the client has unique knowledge which is essential for making informed decisions, and that communication involves learning on both sides.

Changes of attitude, as well as technique, may be needed; one GP suggested that professionals need a 'humility pill'. Courses in listening skills may deepen understanding and respect for clients, but only be as far as the practitioner's beliefs, and values, confidence, and other personal qualities allow. Communication depends on at least two people; courses on communicating with parents which exclude parents are unlikely to increase mutual understanding. Paradoxically they can give professionals a greater confidence which can distance them further from parents. Courses which are partly run by parents could help to increase mutual respect and understanding.

As several interviewees stressed, there is an advantage in not appearing to push parents into a decision, leaving time for them to change their view. This approach could help parents who accept immunisation after due thought. It can also help parents who are determined to refuse, to satisfy parent and professional that they have jointly reviewed the child's best interests fully, as one GP said, to establish a 'solid rock' for future partnership. Yet for professionals who believe 'It's a waste of time talking to them', or 'If they refuse I tell them not to come back', those who adamantly disagree with parents and reject their values, the communication skills could increase confusion. If they give an appearance of respect which is absent, they are then just the velvet glove around the iron fist. The skills were developed through 'non-directive counselling' in which the client's own views are the main issue;<sup>xiii</sup> they were not designed to overcome clients' resistance, and are not a panacea for all disagreements.

### **Conclusion**

The 58 primary health care professionals held varying, sometimes conflicting, views. Many believed that target-setting has introduced new conflicts into immunisation work, as well as some advantages. In conclusion, we suggest ways of addressing the uncertainty and conflict.

It would be helpful to acknowledge the differences and uncertainties, and to establish research programmes on questions which can partly be answered, for example, on the incidence of various reactions to each antigen.

Parents need detailed booklets, as well as the simpler leaflets, about their rational concerns which respect their demanding and responsible position. Some respondents criticised emotive posters which appeal to parents' fear and guilt. They saw a need to establish discussion on a rational basis. Booklets could respond to homeopathic arguments, with clear summaries of research reviews and statistics, and suggested questions to discuss.

Training courses on reconciling opposing values, and working in teams where members have differing values and goals, could help health staff to clarify their own position. They might conclude that accepting parents' refusal, though in some ways unsatisfactory, does allow for appropriately flexible primary health care in a pluralist society.

Primary care teams could review divisions of labour, when different people inform or immunise or treat after-effects. Some staff felt this undermined standards of care, fragmented information and support for parents, and could limit the understanding and divide the responsibility of professionals.

Training in communication skills about technique and manner can divert attention from improving the substance of discussions. Greater attention could be paid to methods of sharing available information with parents.

The HV who attended law lectures, but failed to persuade the GPs to pay more attention to consent, illustrates the importance of linking training with practice. Primary care teams could do short training sessions together, instead of sending off one or two individuals. They could review how responsibility and knowledge are shared, and how their team work might be improved in basic clinical, legal and ethical aspects.

There are no simple answers to the complex questions raised by childhood immunisation, and by attempts to combine high rates of immunisation with respect for parents' decisions. Effort is needed from all concerned, if the uncertainties and deficiencies reported by our interviewees are to be addressed.

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