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European citizens' opinions on immunisation

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KEYWORDS

Immunisation; State compulsion; Parental choice **Summary** As part of a larger study exploring how European citizens' balance issues of public and private interest and the extent to which they are prepared to accept State intervention on a range of public health issues, focus group participants were asked whether childhood immunisation should be a matter of parental choice or State compulsion. The question was debated in 66 (of 96) focus groups held across 16 European countries in 2003. Discussions focused on the concept of risk, trust in health professionals and the State, upholding the status quo, fears over vaccine safety and perceptions of infectious disease as a 'foreign threat'. © 2007 Elsevier Ltd. All rights reserved.

1. Introduction

Childhood immunisation is an effective means of eradicating or significantly reducing the incidence and severity of particular infectious diseases [1-3]. Consequently, the State has an interest in encouraging childhood immunisation, both to provide protection for individual children [4] and to protect the public health through the achievement and maintenance of herd immunity [5].

However, childhood immunisation is not without risk: some children may experience an adverse reaction to immunisation [6]. Once herd immunity has been achieved there is little marginal benefit to either the individual child or the

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public health from vaccinating more children, thus continuing to vaccinate may be unnecessarily risky. Concerns over vaccine safety and/or the reporting of concerns over vaccine safety have polarised the immunisation debate and led to a loss of confidence among some parents and a consequent fall in immunisation coverage in some countries.

Debates over whether particular (childhood) immunisations should be compulsory or voluntary raise a number of issues [1,4,7,8], including questions about individual freedom versus collective responsibility [9–12]: in this case how focus group participants balance the private and public interest when thinking about childhood immunisation. Some perceive compulsion as an infringement of civil liberties and parental rights, and believe that the potential benefits of compulsory immunisation are outweighed by the ethical problems that they pose, primarily for the autonomy of parents [13]. Others maintain that the protection of public health can justify the use of compulsory measures and assert that compulsory vaccination ensures greater equity

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in society since all members share the risks and benefits of vaccination equally [14].

This paper is based on a study that explored which public health interventions a cross-section of people across Europe would be willing to accept; their reasons for accepting or rejecting specific public health policies and their enforcement; and how people balanced public and private interest. This paper reports the study findings in relation to immunisation. At the time the focus groups were held certain immunisations were compulsory in Belgium, Greece, Italy and Poland, with non-compliance theoretically punishable by fines or temporary imprisonment for the parents and refusal of school enrolment for children; financial incentives aimed to encourage parents to have their children immunised in Austria; and financial incentives aimed to encourage healthcare professionals to increase immunisation coverage in Ireland and the United Kingdom [15]. In contrast, immunisation was completely voluntary and without incentives in Denmark, Finland, Germany, the Netherlands, Portugal, Spain, Sweden and other countries (although this is not to deny the existence of social pressure or pressure from healthcare professionals to immunise).

2. Methods

In September and October 2003, 96 focus groups were held across 16 European countries. Immunisation was discussed in 66 groups: 5 groups in Austria (Linz, Vienna), 5 in Belgium (Antwerp, Liege), 1 in Denmark (Vejle), 4 in Finland (Helsinki, Jyväskylä), 1 in France (Tours), 6 in Germany (Hamburg, Leipzig), 3 in Greece (Athens, Salonica), 4 in Ireland (Cork, Dublin), 7 in Italy (Milan, Rome), 5 in Luxembourg (Luxembourg City), 3 in the Netherlands (Amsterdam, Eindhoven), 6 in Poland (Krakow, Warsaw), 3 in Portugal (Lisbon, Oporto), 6 in Spain (Barcelona, Madrid), 4 in Sweden (Orebro, Stockholm) and 3 in the United Kingdom (Glasgow, London). The topic guide was piloted in additional focus groups held in France and the United Kingdom. The focus group methodology enabled participants to discuss issues that they may not have previously considered and to form N. Moran et al.

or challenge their opinions through discussions with other people [16–18].

Focus groups contained an average of eight people per group. Participants were recruited by Market Research companies in each country via a range of techniques: telephone directories, a recruiter database of contacts, and doorto-door and on-street recruitment. In order to reduce the chance that focus group discussions would be biased by people with strong views for or against particular issues, a screening questionnaire was used. Potential recruits were excluded if they responded that they were very active in working for political issues; if they had absolutely no interest in current political and social issues; or if they worked for the government or in marketing or the health industry.

The groups were segregated according to gender; age (20-30 or 45-60 years); marital status; parental status; educational status; and smoking status. The combination of variables in each group was varied in different countries to ensure that each permutation was included. Table 1 provides an illustrative example.

The number of focus groups conducted was large by qualitative standards, but the number of groups in each specific national demographic was proportionally less. Care must be taken if looking for similarities and differences between countries and demographic groups. Historical and legislative differences, linguistic issues and the small sample size involved must all be considered.

It is possible that the findings may have been influenced by the timing of the study. Focus groups were held during September and October 2003 when the global panic surrounding Severe Acute Respiratory Syndrome (SARS) was at a peak. This may have heightened public awareness over the dangers of communicable diseases and thus possibly increased support for immunisation per se and for State powers to impose vaccinations. However, this was also a time when fears over vaccine safety continued to be in the public consciousness in particular countries [19], for example, MMR in Ireland, Italy and the UK [20–23] and the use of mercury as a binding agent in the USA [6,24,25]. In some countries such concerns may have reduced support for immunisation and/or led to greater support for parental freedom to choose. It

Country 1		Group					
		1	2	3	4	5	6
Gender	Male		Х		Х		Х
	Female	Х		Х		Х	
Age	20-30	Х	Х	Х			
	45–60				Х	Х	Х
Life stage	Single/co-habiting, no children yet	Х		Х	Х		
	Married/living as married/living alone but have children living at home with them, or who have left parental home		Х			Х	Х
Education level achieved	Further education achieved (local definition)			Х	Х	Х	
	No further education achieved	Х	Х				Х
Smoker/non-smoker	Smoker	Х		Х	Х		
	Non-smoker		Х		Х	Х	Х

is certainly possible that attitudes may have changed, or indeed may have hardened, in the time since the focus groups were held.

The focus groups each lasted approximately 2 h and were conducted in the appropriate local language. During the 2h sessions, a range of public health policies and potential interventions were discussed, including childhood immunisation, the fluoridation of public water supplies [26], smoking, the physical punishment of children, the legalisation of cannabis, Not In My Back Yard issues (NIMBY-ism) and preferences for a high tax/high State provision society or a low tax/low State provision society. Participants spent no longer than 20 min discussing immunisation. The question on immunisation asked:

Should the decision as to whether to vaccinate their own child be left to the parents? Or should vaccinations be enforced by the government in order to keep diseases (such as measles which can cause more death and damage to more children than the risks associated with the vaccine) out of society as a whole?

This question was intentionally loaded. Childhood immunisation, and in particular compulsory childhood immunisation, is a contentious issue and the question was designed to elicit strong emotions and a focused debate. Each focus group was led by a trained group leader working from a semi-structured topic guide and approved prompts. The prompts were also designed to be dichotomous and provocative, both in support of compulsory immunisation and in support of parental freedom to choose. Participants were presented with these two extreme positions and were not taken through the various types of State compulsion or the range of alternatives between compulsion and parental choice. Rather, it was left to participants to consider and debate possible (preferred) alternatives.

The focus groups were transcribed into the local language and translated into English. As the focus group data was so rich and nuanced, an inductive analysis [27,28] was employed. A coding frame evolved as the transcripts were systematically interrogated by the research team [29]. The data was coded both vertically by issues arising from within topic-based discussions (e.g. debates around compulsory immunisation, concerns over vaccine safety, debates around the necessity and utility of immunisation per se), and horizontally as over-arching themes emerged (e.g. risk, immigration and trust). Transcripts were coded using Atlas.ti software and analysed using a general inductive approach which enabled the research team to explore the themes and issues that were felt to be important by the focus group participants [30]. Similarities and differences across sub-groups (e.g. focus groups in different countries, those with children and those without children) were also explored.

3. Results

The question on childhood immunisation was intended to be broad and to lead participants to debate the extent to which they felt that parents should be free to decide the immunisation status of their children or the State should intervene. The central theme emerging from the focus groups in several countries was the concept of risk discussed in terms of both private interest — 'could immunisation harm my child?' — and public interest—'could non-immunisation harm other people?' The question of parental choice versus State compulsion was often a secondary concern.

This research found no clear correlations between attitudes to immunisation or compulsory immunisation and gender, age, marital status or educational level. Focus group participants with children were slightly more likely to discuss immunisation and to hold stronger views (in any direction) on immunisation. This is likely to reflect their direct experience of thinking about vaccinating their own children. The main differences in attitudes expressed in the focus groups were found at country level. Participants in countries where immunisation is compulsory were more supportive of State compulsion than those where immunisation is voluntary, and participants were more likely to discuss issues around vaccine safety in those countries where vaccine safety had been a recent issue.

3.1. The concept of risk

A significant number of participants questioned the safety of immunisation and expressed concerns over the potential side-effects of vaccines. Where the risk of side-effects was perceived to be high, participants argued against immunisation and were generally opposed to compulsion. Where the risks of vaccination were deemed to be low, or were not discussed at all, participants were more supportive of immunisation. Some believed that with adequate clear information parents would voluntarily choose to have their children immunised and thus compulsion would be both unnecessary and would undermine parental freedom to choose. Others believed that compulsion would be necessary to ensure that children were immunised, either because parents may otherwise forget, or because they may not believe that immunisation is necessary against certain diseases. Some participants argued in favour of immunisation on the grounds that they had been immunised against a range of diseases and had not been adversely affected. In contrast, other participants countered that they had been infected by various diseases in childhood and had not suffered any adverse consequences, thus immunisation against diseases such as measles were perceived to be unnecessary:

"- MMR wasn't about when we was kids, we all had measles, we all had mumps and German measles."

(London-male, 20-30, married, children, further education, smoker)

There was broad agreement among participants that immunisation programmes are beneficial to the public health. Participants praised the eradication of particular diseases (e.g. smallpox), and expressed concern that if rates of immunisation fell, it could lead to epidemics and the potential emergence of new strains of disease.

On a number of occasions, focus group participants placed public health above the health of individual children. The majority of people who argued in favour of compulsory immunisation used public interest arguments as their justification. Although they were not necessarily supportive of State intervention in other areas, they believed that compulsion may be necessary in order for herd immunity to be achieved and maintained and for the public health to be protected.

A number of participants demonstrated an awareness of the potential conflict between private and public interest in the sphere of immunisation. Individuals may not have wanted to have their own children immunised but they realised that if enough other parents thought the same, then the risk of epidemics would threaten the public health and this in turn would threaten the individual health of their children:

''- Well, we are not crazy, but sometimes other people are crazy. You also have to contemplate other people who are not responsible enough for this.

- I think there are certain vaccines that should be compulsory, because some diseases could imply disease for others as well ... So not having this vaccine might affect third parties ...''

(Oporto-male, 45-60, married, children, no further education, non-smokers)

3.2. Differences in countries where compulsory immunisation already exists

In countries where certain childhood immunisations are already compulsory (Belgium, Greece, Italy and Poland), focus group participants tended to support the status quo, at least for those diseases which were currently compulsory in their own countries. Unfortunately it is beyond the scope of this study to determine the direction of causality and ascertain whether the legislation had a normalising effect on public opinion, or whether compulsory legislation was introduced in response to perceived public support for State enforcement. Regardless, this obligation informed the debates in each of those countries where compulsory legislation currently exists. Indeed, some participants in the Polish focus groups queried why they were asked to comment on a law that already exists. On the whole, focus group participants (in each of those countries where some compulsion already existed) supported compulsory immunisation:

"- there is legislation on this

- and it is good that it exists

- ... we have vaccinated our children through this system. The State has imposed this. So I can't give any other answers. I say that we should do them."

(Salonica—male, 45–60, married, children, further education, non-smoker)

In countries where childhood immunisations are voluntary, focus group participants were more likely to oppose compulsion and instead advocate the rights of the parents to decide their child's immunisation status:

"- Parents should have the power to decide, and parents have the responsibility as well"

(Jyväskylä—male, 20–30, married, children, further education, smoker)

Focus group discussions in Germany were particularly illustrative of this support for the status quo. Compulsory immunisation was supported by a majority of the focus group participants in the former East Germany where certain immunisations were previously compulsory. By contrast, a majority of participants from the former West Germany, where immunisation was voluntary, spoke in favour of parental choice and private interest. However, again, the direction of causality cannot be explored further in this paper.

3.3. The 'foreign threat'

Immigration was raised in a number of the focus groups in relation to numerous issues. In relation to immunisation, a small number of participants in Austria, Finland, France, Greece and Italy implied that certain vaccinations are, or remain, necessary because of the risk of disease entering the country through 'foreigners'. Such participants tended to argue that immunisation would not be necessary in their respective countries if it was not for this 'foreign threat'. For example, in Italy, where certain immunisations are compulsory, one participant commented:

"- The State has to promote it, because our State is becoming a multi-ethnic state. A lot of diseases totally unidentified are coming here in Italy and they are serious. There are tuberculosis and malaria in Milan. There are diseases that are kept hidden. That's why the State has to monitor, to make sure and, in these cases, to issue some regulations, issued by Regions. This is because unidentified diseases are arriving."

(Milan—male, 45—60, married, children, further education, non-smoker)

In some countries there was an underlying element of blame (as illustrated in the previous quote), while in other countries participants expressed empathy for those who were not fortunate enough to have had access to immunisation in their native countries.

"There are some things which are coming back. And why? Because there are things brought in by these groups of people who unfortunately didn't have access to these vaccinations, to that kind of healthcare".

(Tours—female, 45–60, single, no children, further education, smoking mix)

In Austria, Finland and Greece, those participants who linked the need for immunisation with increasing immigration primarily referred to the threat from immigrants from the European Union's eastern neighbours. For example, the Greeks 'blamed' the Albanians for the spread of disease, while the Austrians and Finns 'blamed' the Russians. However, the spectre of immigrants spreading disease was only vocalised by a minority of focus group participants.

3.4. Trust

Whether directly or indirectly, issues of trust were raised in all countries. In Belgium, Denmark, Germany, Greece, Italy, the Netherlands, Poland, Spain and Sweden (a cross-section of countries where different compulsory and voluntary immunisation policies exist) focus group participants expressed their trust in the immunisation advice of family doctors, paediatricians, or State health agencies. Participants commonly argued that doctors, health authorities or the State have better access to expert knowledge and thus are best placed to make informed decisions:

"- It is outside of the decision-making competence of most parents. Sure, the situation is different if the parents are medical doctors, but this is probably a small percentage. This decision has to be taken away from parents, because they are simply not competent enough to decide."

(Leipzig—male, 20–30, single, no children, no further education, non-smoker)

Participants in one Swedish group developed their argument into a discussion of act versus omission—in this instance the potential harm caused to one's child through the act of immunisation, versus the potential harm caused to one's child if the parent omits to immunise and the child later contracts the disease. Consequently, the majority of participants in that group went on to support compulsory immunisation on the grounds that the decision should be taken by experts, not parents, despite the fact that immunisation is voluntary in Sweden.

A number of participants from other countries stated that they would like more access to information about the risks and benefits of immunisation versus non-immunisation so that they may make more informed decisions. For example, a participant in one of the Finnish focus groups (where immunisation is voluntary) explained:

"-... I am taking the vaccination, but I don't understand ... I have read a lot about these things and thought about them. I choose to take them, but I don't think they give you any options, really. This is a good example of a situation where an independent party, whatever it might be, should inform people more".

(Jyväskylä—male, 20—30, married, children, further education, smoker)

Where participants lacked confidence in the advice of their doctors, politicians or State health agencies, they were more likely to express concern over the safety of vaccines and were less inclined to have their own children immunised.

Fears over the safety of vaccines, in particular the measles—mumps—rubella triple-vaccine (MMR), were raised in a number of focus groups in Ireland, Italy and the UK. Participants made reference to cases and media reports where they believed that children had suffered from serious, and in some cases fatal, side-effects of vaccination, and in some cases stated their opposition to having their own children immunised:

"- Right, see, I was, I was for it [MMR], I let my son have the first one and then when it all came out and it was all basically, it came out it could cause this, it causes this, and my son is a very bright child. I absolutely flatly refused to let him have the booster, simply because if he's come out like that I don't want to spoil his intelligence by giving him something."

(London—male, 20—30, married, children, further education, smoker)

Participants were divided in how they weighed the perceived risks of MMR. Some argued that the link with autism had not been proven and even if it existed the risk of developing autism from the vaccine would be less than the risks associated with contracting a vaccine-preventable disease. Others argued that, partly owing to the risk of side-effects, immunisation should be a matter of parental choice.

Trust in the State and public health authorities was influential in public perceptions of vaccine safety. For example, participants in two of the UK focus groups referred to the fact that then British Prime Minister Tony Blair had not disclosed whether or not his own young son had been given the MMR vaccine. This fuelled participants' safety fears and jeopardised their faith in the vaccine:

''- If the prime minister won't let his own son have it then why should we put our faith in it with our kids?''

(London-male, 20-30, married, children, further education, smoker)

Focus group participants in Ireland and the United Kingdom also expressed concern over the concept of 'immune overload'. Participants from these countries were more likely to question the safety of multiple vaccines, in particular the MMR triple-vaccine, and discuss their perceptions of the relative merits of single antigen vaccines.

In countries that had not (recently) experienced vaccine scares or where vaccine scares had not been the focus of media attention, vaccine safety was not discussed by focus group participants.

4. Discussion

This part of the study set out to explore European citizens' opinions on the extent to which childhood immunisation should be a matter of parental discretion or should be strictly enforced by the State. Participants were not asked to debate different immunisation policies. Rather, the study aimed to explore how people across Europe weigh the competing claims of private and public interest in relation to a contentious issue such as childhood immunisation. In many of the focus group discussions this question was interwoven with concerns over risk and vaccine safety, questions around trust, access to information, debates around whether certain immunisations were even necessary, and concerns that any continuing need for immunisation was due to the threat of disease being brought into the country by immigrants.

A systematic review of qualitative studies looking at parental attitudes and beliefs toward immunisation found that in more than half of all the studies reviewed, barriers to childhood immunisation included concerns over the risk of adverse side-effects, distrust of those advocating the vaccines, poor communication with health-care staff and a lack of awareness of the immunisation schedule [31]. Fears of side-effects and concerns over the safety of particular vaccines have been reported as factors associated with low immunisation coverage in numerous other studies [32-34] and were common themes in the focus group discussions. Studies also suggest that parents fear overloading the child's immune system with multiple vaccines [35,36]. Discussions about 'immune overload' within the focus groups were more prominent in countries where the MMR scare received a lot of negative media coverage, most notably in Ireland and the United Kingdom.

However, not all studies support the notion of a correlation between the health beliefs of parents and the immunisation status of their children [37]. Instead, some studies report that immunisation status is more closely related to socio-demographic characteristics [38], with low immunisation coverage correlated with low socioeconomic status [39]. However, the only discernable socio-demographic difference in attitudes toward immunisation noted in the current study was that focus group participants who were also parents tended to have stronger views on immunisation. Whether this was support for or against immunisation correlated with the intensity of recent vaccine scares and participants' expression of trust in the reassurances of family doctors and State public health authorities.

Focus group participants who supported compulsory immunisation commonly argued that health authorities and the State have better access to experts and information, that immunisation is generally in the best (private) interests of children, and that the achievement of herd immunity benefits public health and the public interest. The focus group data indicate a correlation between support for compulsory immunisation and the existence of compulsory immunisation policies in certain countries. It is not possible to confirm the direction of causality as the correlation could suggest a degree of normalisation whereby laws on compulsory immunisation gradually become part of a cultural norm or, conversely, the legislation could reflect the public's concern to maintain high levels of immunisation coverage and/or to reduce the incidence of particular childhood diseases. Similarly, in relation to trust, the existence of compulsory measures could imply any number of positions on a spectrum ranging from State lack of trust in parents to immunise their children in the absence of compulsion; public trust in the advice of the State (and hence support for compulsion in the belief that not all parents would have their children immunised without such pressure); or it could suggest that the public do not trust the advice of the State and thus have to be forced (by legislation) to comply with State policy.

In some countries, a small number of participants spoke of the 'foreign threat' whereby immunisation was deemed necessary to combat diseases being brought in from abroad. Where this 'foreign threat' was raised as an issue, participants tended to 'blame' the European Union's eastern neighbours, notably the Albanians and the Russians. However, this was very much a minority voice, with generally only one or two participants from each country where the issue was raised making reference to a 'foreign threat'. The fact that the timing of the focus groups coincided with the global panic over Severe Acute Respiratory Syndrome (SARS), a disease spread between countries largely through international travel, could have influenced such comments.

Access to information regarding immunisation was also raised in the focus groups. A number of participants commented that they would like to have more information in order to make an informed decision. This reflects findings from other studies, where parents who felt they did not have enough information were less confident in the safety of vaccines and had more negative attitudes toward their health-care providers [40].

Focus group participants also debated whether building natural immunity to infectious diseases is preferable to immunisation and/or whether vaccine-preventable diseases were actually all that serious. The latter point is illustrative of the immunisation paradox, a phenomenon whereby the success of previous public health measures, mass immunisation and consequent herd immunity have reduced the prevalence of particular diseases leading parents to believe that the current threat of infection from such diseases is minimal. Some parents may thus refuse to have their children immunised on the grounds that the risks associated with immunisation, though small, are perceived to outweigh the benefits [41]. Paradoxically, the success of immunisation programmes may ultimately reduce take-up rates with the potential for future epidemics of preventable diseases [42–44]. Again this reflects findings from other studies [45,46].

A key finding in this study is the positive relationship between parental trust in health professionals and their decision to immunise. This finding has been supported by other research [31,47,48]. Studies from across Europe and the United States have shown that physicians who were concerned about the safety of particular vaccines were less likely to vaccinate or recommend certain vaccinations and this correlated with low levels of childhood immunisation [49–51]. Similarly, parents within the focus groups who stated that they did not trust the advice of health professionals also said that they were less likely to consent to their children being immunised.

Generally, in countries that had not experienced vaccine scares, or where such scares (at home or abroad) had not been widely reported in the media, or where participants spoke of their trust in the State and public health authorities, the potential risks or side-effects of immunisation, however small, were not debated. Sweden provides an interesting example. The MMR scare was widely reported in the Swedish media and was met with a brief decline in immunisation coverage. However, once the public health authorities provided clear and open information relating to the potential risks and benefits of immunisation, high rates of coverage were quickly restored. This suggests that public trust in public health authorities was largely maintained or secured. Indeed, none of the Swedish focus group participants spoke of fears over vaccine safety. By contrast, where participants spent most of their time debating the relative risks of immunisation versus non-immunisation or where they opposed immunisation on the grounds of safety concerns, this tended to correlate with an expressed lack of trust in the advice and reassurances of the State and public health agencies.

On the whole, focus group participants were supportive of immunisation and recognised the potential health benefits to individual children and to the wider society of high rates of immunisation coverage. Even in countries where vaccine scares were in the public consciousness and some participants expressed concern over exposing their (hypothetical) child to immunisation, their concern was over the type of vaccination (for example, multiple-antigen vaccines) rather than about immunisation per se. The extent to which participants supported the notion of compulsory immunisation depended largely on whether certain immunisations were already compulsory in their country, whether they trusted the State and public health professionals to take immunisation decisions on their behalf, whether individuals felt they had enough information to make their own informed choices, and the extent to which they felt that compulsion was necessary to ensure that enough other people in their society had their children immunised to achieve herd immunity. Each of these factors is influenced by a myriad of other assumptions, actors and institutions, including family, community, media, religious beliefs, political structures and historical factors. Each could be the subject of illuminating further research.

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