Health and Social Care Committee

Inquiry into the measles outbreak 2013

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Introduction

Many of the factors influencing vaccine uptake apply to all vaccines, not just MMR. Presented below is therefore a general discussion as well as some issues specific to MMR vaccine. However the next vaccine scare may well be to do with another vaccine already in the programme or, bearing in mind the major changes to the schedule currently being implemented, it could be a new vaccine.

Background to the MMR vaccine safety scare

The combined measles, mumps and rubella (MMR) vaccine was introduced to the UK in 1988.

Uptake of the vaccine rose rapidly to a high of 92%. In 1992, two brands containing the Urabe strain of the mumps vaccine virus were withdrawn after it was noted to be associated with an increased risk of aseptic meningitis (Miller *et al*, 2007). This did not appear to have a deleterious effect on uptake. In 1995, a paper was published suggesting a link between measles vaccines and the development of bowel disorders in adulthood (Thomson *et al,* 1995). This was associated with a small decline in the uptake of MMR vaccine. In 1998, the same group of researchers published observations on 12 children with pervasive developmental disorders and bowel disease and suggested that the latter may have led to the former (Wakefield *et al*, 1998). In eight children, the history of the onset of symptoms coincided with receipt of MMR vaccine. Although the researchers stated in the paper that ''we did not prove an association between measles, mumps, and rubella vaccine and the syndrome described'', and an accompanying commentary was heavily critical of any suggestion of such a link, (Chen and DeStefano, 1998), the story attracted much attention in the media

(especially between 2001-2). This was largely fuelled by a paragraph in the press release accompanying a press conference: ''The majority opinion among the researchers involved in this study supports the continuation of MMR vaccination. Dr Wakefield feels that vaccination against the measles, mumps, and rubella infections should undoubtedly continue but until this issue is resolved by further research there is a case for separating the three vaccines into separate measles, mumps, and rubella components and giving them individually spaced by at least 1 year''(Horton 2004). Subsequently, public confidence in the vaccine was dented and uptake of the vaccine in England fell to 79%, with some parents seeking the single antigen components. (taken from Elliman and Bedford, 2007).

Factors influencing immunisation uptake

High vaccine uptake depends on a range of inter-related factors:

Good information systems:

- Are required to implement and monitor immunisation programmes locally and nationally.
- Should be used locally to send out invitations for childhood immunisations, produce lists of those who do not attend and should be followed up. Reminder and recall systems, alone, have been shown to increase coverage by up to 20% (Jacobson and Szilagyi 2009)
- Can produce general practice level coverage data for local action. Feedback of performance to vaccine providers at local level is important for improving coverage. (Crowcroft 2009).

Well organised immunisation services:

- Need a lead person to take responsibility and coordinate the service,
- Should provide a source of expert clinical advice.
- Should provide flexible services – immunisations need to be provided in a variety of settings, in addition to primary care and schools (for older children). These could include hospitals, children's centres and nurseries.

- Should involve all members of the team, including administrative staff- to ensure everyone is providing the same positive message about immunisation and giving accurate information.

Well informed, motivated and enthusiastic staff

- Health care professionals (HCPs) who deliver immunisation services, (in general practice, nurses and school nurses administer vaccines and health visitors and GPs advise about them) need both to be well informed about the principles and practice of immunisation, but also able to communicate effectively with parents, children and young people. This is not simply a case of providing a standard set of information. Most parents, even those who accept vaccination, have questions about the vaccines. HCPs need to assess what information parents need, i.e. what they know and have read, as well as their individual concerns, and tailor the information accordingly. Some questions are complex and require both a high level of knowledge and confidence to discuss them, as well as a significant amount of time.
- The Health Protection Agency (HPA now part of Public Health England - PHE) issued guidance on minimum standard for training and the content of a core curriculum for all those involved in immunisation in 2005. It is not clear to what extent immunisation training adheres to this guidance. Provision of immunisation training locally is variable and maybe provided by local experts, or bought in from universities or independent companies. In addition, two e-learning packages are available. Ideally these should augmented with training provided locally where local issues are discussed and local expert sources of advice are introduced.

Vaccine acceptance

- Overall coverage rates for childhood vaccines are very high. However, children who are not fully immunised tend to fall into two main groups: partially immunised children who simply do not complete the immunisation course (varies in size, but probably 3-5% on average) and children who are totally unimmunised (about 1-2% but maybe higher in some geographical areas).
- The characteristics of these two groups differ (Samad *et al* 2006a):

    - Parents of unimmunised children often have strong beliefs and are less likely to consider vaccination to be safe or to be necessary. In one large UK study, almost a half of the parents of 228 unimmunised children reported this to be due to their beliefs and attitudes (Samad *et al* 2006b). Mothers of these children are often older and more highly educated.
    - Children who commence the immunisation course but do not complete it are more likely to have social or practical issues making access to immunisation services difficult (32% of 697 partially immunised children (Samad *et al* 2000b)). Among this group are parents who do not object to immunisation, but for whom social or family pressures may mean that they do not get round to completing the course.
    - Children at greater risk of being partially immunised include:
        - Children in large families (Li & Taylor 1993; Samad *et al* 2006a)
        - Younger mothers (Samad et al 2006a) who are lone parents (Sharland *et al* 1997; Samad *et al* 2006a)
        - History of hospitalisation in the child (Samad *et al* 2006a).
- These two groups, partial and non-immunisers, thus may require different interventions.
- Services for partial immunisers in particular need to be accessible and flexible. Health care professionals should consider offering opportunistic or domiciliary immunisation and reviewing immunisation status when families attend primary care for other reasons as well as in other health care settings, particularly hospitals.
- Vaccine uptake also tends to be poorer among:
    - looked after children (Ashton-Key and Jorge 2003)
    - those with disabilities or other long term conditions (Peckham *et al* 1989; Tuffrey and Finlay 2001)
    - travelling communities (Dar *et al*, 2013)
    - certain ethnic groups –though maybe specific vaccines (MMR and Somali population Schickler and Bedford Unpublished).

- For non-immunisers, or hesitant immunisers, the required intervention relates to providing information that is tailored to respond to parents' questions and concerns, at a level of complexity appropriate to the individual. In practice, this may mean that some parents require a lot of detailed information, including lengthy discussions with different health

care professionals as well as written material. Some parents will not change their mind, despite this.

- Among parents who accept vaccines for their children, some will accept vaccine without question (approx. 30-40%) others will be hesitant or cautious (approx. 60-70%). These parents in particular will often have many questions and concerns about immunisation. Another small group of parents may request to have certain vaccines omitted. (Leask *et al* 2012).

Parental Factors Affecting Uptake of MMR vaccine

- In a large UK study of factors influencing uptake of MMR uptake among children born in 2000-2002, at the height of public concern over the safety of MMR vaccine, children were more likely to be unimmunised against MMR if they lived in larger families, if their mother was over 34 or under 20 years of age when then child was born, or they were a lone parent. Higher educational attainment and smoking in pregnancy were also risk factors for non-immunisation. Girls were less likely to be unimmunised than boys. (Pearce *et al* 2008). Children were at increased risk of having single antigen vaccines if their mother was older and more highly educated and had a higher income.

- Reasons given by the 879 parents, whose children had not had the combined MMR vaccine, were mainly that they had made a conscious decision (67%) because of fears over vaccine safety, fears over possible link with autism and negative media publicity.

In a systematic review of 31 studies conducted between 1997-2004 exploring parental decisions about combination vaccines including MMR, in comparison with vaccine accepting parents, those who declined combination vaccines were: (Brown *et al* 2010):

- Less likely to perceive vaccines to be safe and effective
- Less likely to consider the diseases to be serious and for their child to be likely to catch them
- Less trusting in the health care system and the Government
- Less satisfied with immunisation information they had received
- More likely to believe MMR vaccine causes autism
- Less satisfied with their immunisation related interactions with HCPs

- More likely to view media reports favourably
- More likely to have experienced vaccine adverse events
- More convinced of the benefits of single vaccines
- More concerned about immune overload
- Less likely to view vaccinating as a positive social responsibility
- Less likely to have vaccinated previously and to plan to do it again in the future
- Less likely to anticipate regret as a consequence of not vaccinating
- Less likely to consider their HCP supports their decision
- Likely to have started thinking about the vaccination decision earlier
- Less likely to perceive that current vaccine research is adequate
- More likely to express preference for natural immunity
- Less happy to defer to medical advice about vaccines
- Less like to perceive their peers as supportive of their decision

- Department of Health conducted annual tracking studies 1996-2006 among about 1000 parents of young children and reported that by 2006 more parents were confident in the safety of MMR vaccine. Importantly a consistent finding over this 10 year period was that parents were more likely to trust the information given to them by their GP, health visitor or practice nurse than that given to them by the Government. (Smith *et al*, 2007)

- A more recently conducted small study among 24 mothers of children under three years of age who planned to either accept, postpone or decline their child's first MMR dose reported that parents who were rejecting MMR vaccine expressed views which were anti-immunisation in general rather than specifically anti-MMR. Those that were intent on using single measles, mumps rubella vaccines felt that MMR vaccine was unsafe but were not clear why they felt this to be the case. This may suggest that, for some parents of young children, MMR is now considered to be just another vaccine and not one that any longer warrants special concern (Brown *et al* 2012).

- An analysis of factors affecting catch up by 5 years of age of 751 children who were unimmunised with MMR at 3 years reported that those who partially (1 dose) or fully caught up (2 doses) with MMR tend to be those children whose families experienced practical issue or access issues,

whereas the parents of children who remain unimmunised by 5 years of age are more likely to have made a conscious decision not to accept the vaccine. Among this group parents tend to be more highly educated (Pearce *et al* 2013 accepted for publication).

Parents' Perceptions of vaccines and diseases

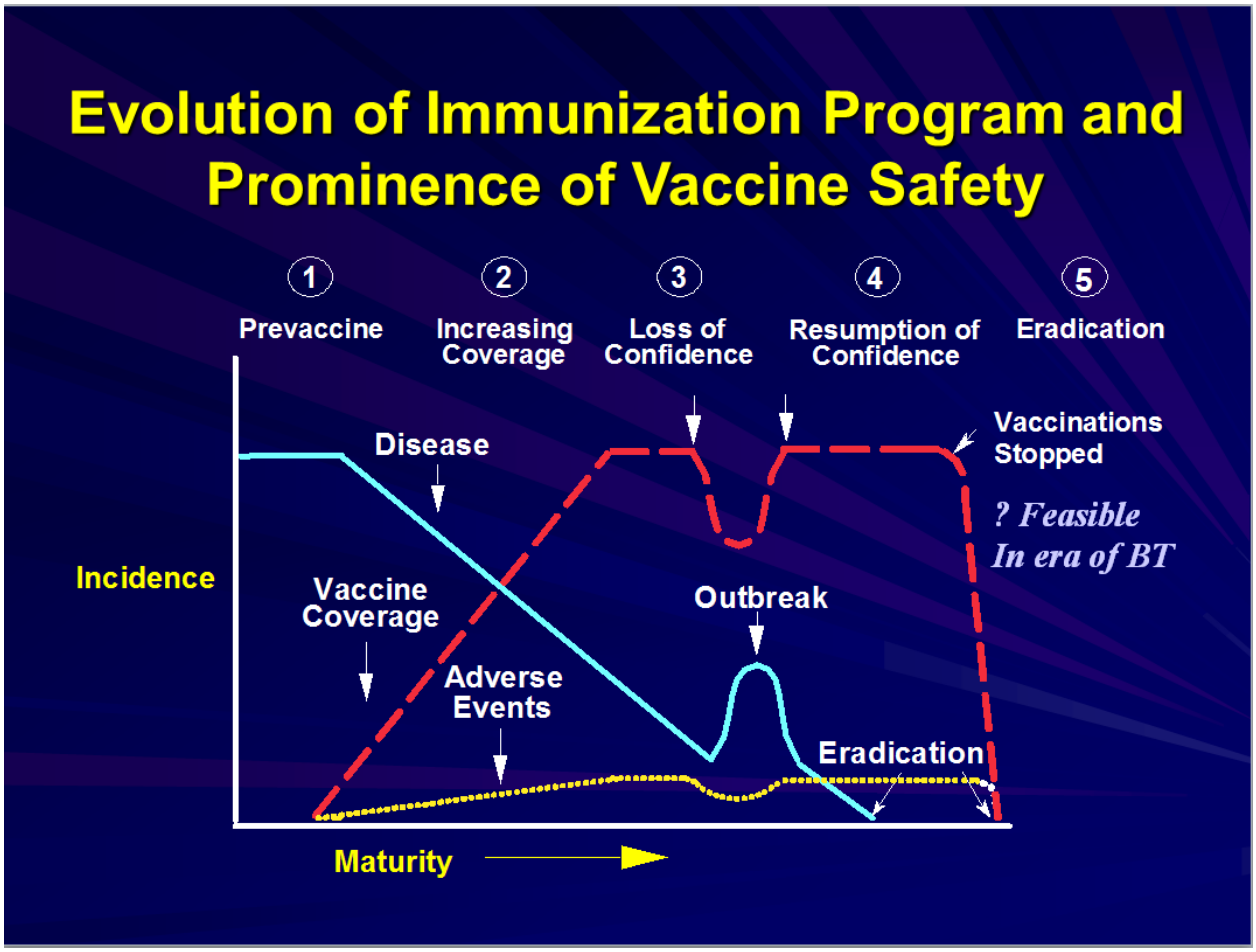
- Parents' attitudes are critically important, in particular concerning the safety and
effectiveness of vaccines and the seriousness of diseases (Peckham 1989). These will be influenced by prior beliefs and experience as well as by the advice and information they gather from a variety of sources, including health care professionals.

- As might be predicted, parents who view the diseases as serious and the vaccines as safe are more likely to have their child vaccinated than parents who think otherwise (Peckham *et al* 1989, Sutton & Gill 1993). The solution to this would superficially appear to be simply one of providing these parents with evidence-based information about the seriousness of disease and safety of vaccines. However, parents who have vaccinated their children also express concerns about vaccine safety, and it is clear that the relationship between perceptions and behaviour is complex (Evans *et al* 2001, Raithatha 2003, Salmon *et al* 2005).

- Vaccines differ from other interventions in that they are administered to healthy individuals at the instigation of health care professionals and so there is a greater ethical imperative to show that their benefits outweigh the risks. Although there is a significant body of evidence, both from research and experience, showing that most vaccines have very low rates of serious adverse reactions, the perception of risk and what is acceptable differs not only between individuals, but alters depending on levels of herd immunity and, therefore, disease in the local population.

- Part of the perception of risk involves the definition of safety. Vaccines are referred to in official literature as being 'very safe'. While this is true, what it really means is 'relatively safe'. Nothing is totally risk free. For vaccines, the adverse side-effects are well-documented, for example, there is a risk of febrile convulsions within 6-11 days of the MMR vaccine of 1 in 3000 doses

(Farrington et al 1995), whereas the risk of convulsions with natural measles infection is reported to be 1 in 100. Clearly there are greater risks associated with the natural infection than with the vaccine. This balance of risks and benefits changes when vaccine uptake is high and the likelihood of catching an infection diminishes; all the risks are then associated with the vaccine. However, this is a delicate balance as any reduction in vaccine uptake may once again lead to a resurgence of disease. This has been graphically portrayed by Bob Chen (Chen 2005)



- Studies report that some parents who decline to have their children immunised do so on the basis that they believe vaccines do more harm than good, that the diseases they are designed to prevent are not harmful and may even be beneficial, by strengthening a child's developing immune system (Evans *et al* 2001, Rogers and Pilgrim 1995, Smailbegovic *et al* 2003; Samad).

- Anti-vaccination groups disseminate the view that the risks of vaccines are far greater than is acknowledged and, in addition to short-term risks, may

have long-term side-effects. Diabetes, cancers, atopy (asthma, eczema and hayfever), multiple sclerosis and autism have all been reported, albeit misguidedly, to be associated with receipt of vaccines.

- Perceptions of disease severity also determine whether or not a child is immunised, but there is disagreement over the severity of some infections between the orthodox medical community and other health care providers, for example, homeopaths (Schmidt & Ernst 2003). It is argued that the death rate from measles was declining long before vaccines came in and that vaccination has had a minor and, possibly, even no part to play (Schiebner 1993). Such extreme views are not supported by the significant body of scientific evidence, but are commonly expressed, and every practitioner will have been challenged to respond to them.

Decision to immunise

The decision to immunise a child is a dynamic process and may change over time. Attitudes to vaccines and diseases are influenced by a range of other factors including prior beliefs about health and medicine, use of alternative or complementary therapies, advice from parents, friends and health care professionals, as well as the influence of the media and more recently the Internet and Social Media. Many studies report health professionals to be the key source of information for parents about immunisation.

The experience of the immunisation process itself may also affect acceptance of further vaccines (Harrington *et al* 2000).

- Evans *et al* (2001) reported that many parents find the decision about immunisation difficult and stressful, and parents have also been described as experiencing severe emotional distress at the prospect of their child being immunised (Harrington et al 2000). Such experiences can lead to failure to complete immunisation courses and to decline immunisation for future children.

- Health care professionals need to recognise that some parents may need considerable time and discussion before they feel able to make a decision and to provide services that cater for this.

- McMurray *et al* (2004) highlighted the fact that some professionals have a tendency to view a parent's attendance at clinic as an indication of informed consent when, in reality, at this point parents may still have questions and professionals should be using that opportunity to offer information and elicit questions as a matter of course. Parents appreciate health care professionals who are empathetic, understand that they may have concerns and who respond appropriately (Harrington *et al* 2000).

- Trust in the source of advice has been found to be pivotal. For example some parents express a lack of trust with the government (BSE, etc. having dented their faith), with the Department of Health. However most say they can trust their own individual GP or health visitor. This emphasises the important role these professionals have.

- However, studies conducted in the early 2000s at the height of the MMR vaccine safety scare reported that some health professionals (GPs and Health visitors) were:
    - poorly informed about vaccines (Cotter et al 2003, Harris et al 2001, Henderson et al 2004, Petrovic et al 2001)
    - did not feel completely confident about explaining specific vaccine issues (Henderson et al 2004, Petrovic et al 2001)
    - disagreed with or had reservations with some vaccine policies (Henderson et al 2004, Petrovic et al 2001)
    - did not use or are not aware of nationally available resources on immunisation (Cotter et al 2003, Petrovic et al 2001)
    - believed that single measles, mumps and rubella vaccines should be available on the
    - NHS (Macdonald et al 2004).
    - had lost confidence in the safety of MMR vaccine (Smith et al 2001)
    - expressed reservations about giving their own child specific vaccines (Brownlie & Howson 2006, Petrovic et al 2001).

Although these findings cannot be extrapolated to all health professionals, it may in part explain why the MMR vaccine safety scare took hold.

Lessons for the future

The uptake of MMR and other vaccines, in children going through the system now is good, though there is still room for improvement. It is important to make full use of the guidance already in existence.

2009 - NICE "Reducing Difference in the uptake of immunisations". This provides guidance on the action that should be taken, and by whom, to optimise immunisation uptake. This allows one to redirect resources to children less likely to be immunised without increased input. (NICE 2009)

2012 – Health Protection Agency "Quality criteria for an effective immunisation Programme". Defines the key elements required for the implementation and delivery of a safe, equitable, high quality, efficient immunisation service which is responsive to the needs of vaccine recipients and/or their carers. http://www.hpa.org.uk/Publications/InfectiousDiseases/Immunisation/1207Qualitycriteriaforimmprogramme/

2013 – Monitoring of the media can provide early warning of a potential issue. This may arise within a country or anywhere in the world and with the advent of social media scares can travel faster than any infectious disease, but an issue may be recognised before it 'takes off'. A media surveillance system has been established to monitor public concerns about vaccine Globally (Larson H *et al*, 2013).

To some extent, the MMR scare was predictable. Prior to the publication of the Lancet paper in 1998, there had been some indication of what was coming. Up to then there was no research into a possible link between MMR vaccine and autism. However, the accompanying commentary in the Lancet, by two American vaccine experts, did point out the limitations of the research. If more experts had been willing to speak out and journalists had been better informed, the scare might have been dealt with quicker. The Science Media Centre trains scientists in presenting their case and how to interact with the media. They also lay on sessions in relation to particular topics where experts are brought together with journalists, so that hopefully the journalists better understand the issues.

Should immunisation be legally required?

Inevitably any outbreak of disease prompts discussion about the need to introduce a legal requirement for immunisation.

- Few countries have compulsory vaccination
- In, USA, there is a requirement for children to be immunised before entering school – this cannot increase uptake in younger children
- Exemptions on religious and philosophical grounds are allowed – States vary in their level of enforcement.
- There is evidence that vaccine refusal is increasing In USA and 1 in 10 use an alternative, sometimes incomplete schedule (Dempsey et al 2011). It is not clear how much of this is concerns about vaccination and how much is a reaction, in principle, to what is seen as an infringement of parental choice. The general view in UK is that we have achieved high uptakes without the need to legislate. The uptake of MMR vaccine among 2 year olds in USA and UK differed little in 2011.
- If legislation were introduced, or benefits were linked to immunisation, there is the potential to widen inequalities in child health & well-being (Elliman and Bedford 2013)
- A case can be made for checking immunisation status at key points i.e. entry to nursery and school which acts as a reminder to parents, and of excluding unimmunised children from communal groups in event of an outbreak

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