Rubella and ethnic minorities project

Outcomes

- Partnership between Sense, community support organisations from minority ethnic communities and local health professionals
- Contact with organisations working with those who enter the country
- Dissemination of information about rubella and rubella immunisation
- Reduced rubella susceptibility in the communities we work through
- A report outlining methods used and impact of the project and how the results could be replicated

Introduction/background

This project was funded by the Department of Health (DH) for three years. The project commenced at the end of September 2008 and was undertaken by a project officer until November 2009. A replacement project officer then undertook the remainder of this project from the end of May 2010. With the absence of a project officer for six months, there was slippage in the project and taking account of this and with permission from the DH, the project completed at the end of March 2012. This project was intended to explore Sense and other’s knowledge of rubella and rubella immunisation within community networks where it is known that rubella susceptibility is high, with the ultimate aim of raising awareness and increasing MMR uptake in these communities.

Literature review

What factors influence uptake of the MMR vaccine among ethnic groups susceptible to rubella infection?

This question can be broken down into several parts. First, the question of what factors influence uptake of immunisation in general and specifically the MMR vaccine; there is a large body of literature covering this topic at both a population and individual level. Second, the question of ethnicity; whether ethnicity is found to be a significant
predictor at a population level, and whether the factors affecting MMR uptake found in individuals in the general population are shared by members of certain ethnic groups. Possible differences between ethnic groups could arise from correlates with ethnicity (in the UK) such as socio-demographic or economic factors, or at an individual level from beliefs or attitudes resulting from traditions or knowledge in the individual’s home nation or culture, the process and experience of migration, or attitudes towards health or health service provision in general.

It has long been recognised that women from ethnic minorities have a higher susceptibility to rubella and this has led to their babies being disproportionately represented in congenital rubella births (Miller et al, 1987, 1997 and Sheridan et al, 2002). Rubella susceptibility rates of women in north London were analysed and similarly revealed higher rates amongst ethnic minority women. The susceptibility of British born pregnant women was less than 2%. Whereas 4% and 8% of women originating from Asia, Africa and the Mediterranean region were susceptible (Tookey et al, 2002). Higher susceptibility rates were present within these groups during their first pregnancy. The most vulnerable group that was identified were Sri Lankan women with susceptibility rates of 15% and rates as high as 23% in their first pregnancy.

A selection of the twelve most comprehensive, relevant, and recent studies have been analysed in depth. These studies included those using census or large-scale population data (Bhopal et al, 1988; Hawker et al, 2007; Pearce et al, 2008; Wright et al, 2005) focus groups, questionnaires, interviews etc (Alfredsson et al, 2004; Brown et al, 2011; Evans et al, 2001; Mixer et al, 2002; Prislin et al, 1998; Smailgebovic et al, 2003) and reviews (Brown et al, 2010; Mills et al, 2005). The focus group, questionnaire, and interview based studies into attitudes and beliefs suggested a range of factors relating to knowledge and concerns about vaccines and related diseases, the balance of risk and benefit to one’s own child and to society, the information available from healthcare professionals and government and the manner in which it is delivered, and practical issues such as childcare or travel to and from a clinic. Interesting factors include a widespread belief that immunity gained through actually suffering a disease is somehow qualitatively ‘better’ than the immunity from a
vaccine; and the belief that a parent may shelter their child from disease via diet and protection from non-infectious harms, or that their child is otherwise somehow unlikely to be susceptible to a disease.

A selection of the studies discussed ‘demographic’ factors such as ethnicity/race, deprivation or socio-economic status (SES), education, and culture. Findings for some of these factors are mixed. For instance, in general it appears that lower uptake of immunisation is related to lower income (Pearce, Law, Elliman, Cole, & Bedford, 2008) and education but that more affluent and well-educated parents are more likely to reject the MMR virus; low uptake in deprived groups is related to deprivation and obstacles to access, while in affluent groups it is related to media exposure and concerns about links with autism, Crohn’s disease etc. Texas, Prislin, Dyer, Blakely & Johnson (1998) found that increasing education was correlated with a decrease in concerns about vaccine safety and trust of medical professionals, but increased concern about medical contra-indications.

Wright and Polack (2005) suggest a general link between low qualifications, lower proportion of households working in managerial or professional positions, and deprivation and higher MMR uptake, and suggest that uptake of MMR declined more slowly in areas with higher proportions of households with no qualifications (although the format of their population data-based study may be subject to ecological fallacy). Although Smailgebovic, Laing, and Bedford (2003) did not report correlations with SES, they indicated that the population studied in Hackney was mostly deprived, and they found that 17% admitted that they did not know how vaccines might work, or suggested risks of immunisation such as “Vaccine can cause altering DNA”.

Findings related to ethnicity are equally mixed. On average, ethnic minorities (especially Black Caribbean) were found to have lower immunisation coverage, however there is a consensus that Asian groups have higher (if not the highest) coverage out of the entire population (Mixer, Jamrozik, & Newsome, 2002; Hawker, Olowokure, Wood, Wilson, and Johnson, 2007). Hawker also found that rates of immunisation among the ‘Black Other’ ethnic group were as high as
those among the Asian group before 1998, but fell drastically to the same level as the ‘White’ ethnic group post-1998. Mixer et al. (2002) propose a variety of suggestions to account for this, including correlations with higher SES in some studies; greater reliance on the advice of elders, who are more aware of the seriousness of related disease; greater trust in Western medicine; or a paradoxical protective effect of poor levels of English that prevents exposure to the MMR controversy in English newspapers (also in Bhopal & Samim, 1988). Bhopal and Samim also suggest other explanations, such as a greater emphasis in Asian traditional medicine on prevention rather than cure, or stronger family networks that could provide childcare for a mother as she takes another child to be immunised.

Although Mixer et al. report a significant relationship between ethnicity and SES; they suggest that the strong correlation found between ethnicity and MMR uptake is independent of socio-economic status. Prislin et al. (1998) found that ethnicity/race was significantly rated to concern about natural immunity, medical contraindications and protection from disease in Texan parents. Some studies mention ‘anecdotal’ factors that may affect difference in uptake between ethnic groups, however these tend to be incidental or hypothetical. Overall even studies that focus on ethnic minorities do not focus on specific cultural features of certain ethnicities, instead comparing ethnic groups with factors that affect the general population.

Brown, et al.’s (2011) study into the creation of a valid and reliable evidence-based measure found that their comprehensive questions accounted for only around half of the variance, leading them to suggest that “either some highly influential predictors were omitted, that parents were not completely truthful, or that a substantial proportion of MMR decision-making is unpredictable …” (emphasis added). Evans et al.’s (2001) findings suggest that parents who immunise their children and those who choose not to, do not differ significantly in many of their beliefs and attitudes towards immunisation, and that any difference was due to attitudes towards compliance. Similarly, Brown et al. (2010) found that identical numbers of parents who accepted and rejected MMR had attitudes reflecting distrust of healthcare providers/government, and a perception of poor communication. However, Pearce et al. (2008), in
their study of 14,758 children in the Millennium Cohort, found that 74.4% of parents who had refused immunisation for their child, had reported that they made a conscious decision to do so on the basis of fears about the safety of the vaccine.

**Method**

Initially a consultant was employed to identify populations and groups that the project should target. The consultant identified two potential organisations to work with, New Links in Peterborough and the Nottingham Pakistani Community Organisation. The consultant’s report concluded that migrants from the following communities were potentially important targets for the intervention:

- **Western Pacific Region:** China, Cambodia and Vietnam
- **South East Asian Region:** Bangladesh, Sri Lanka and Pakistan
- **Eastern Europe:** Bulgaria, Latvia, Lithuania, Romania, Tajikistan, Poland and the Russian Federation
- **Sub Saharan Africa:** the Central African Republic, Kenya, Uganda, Zimbabwe and South Africa.

It was agreed that London, Peterborough and Nottingham were the areas that would be selected to carry out activities during the course of the project. During the first six months of the project 15 community based organisations working with the Bangladeshi and Sri Lankan communities were visited and informed about the project. Eight of which responded positively towards receiving information or a workshop about rubella and MMR.

**Steering Group**

A steering group was established to advise on the direction and focus of the project, and met at various intervals during the course of the project. Sense collaborated with experts in immunisation, rubella, health psychology and health in minority ethnic groups. Sense membership of the steering group varied during the project as various people moved on from the organisation.
Activities

Focus groups were held to identify issues and attitudes towards rubella and MMR immunisation. Questionnaires were carried out in Peterborough and Nottingham; the findings of these activities have been discussed later in the report. Workshops, presentations and awareness sessions about rubella and MMR were also carried out within community settings and also in the statutory and voluntary sector.

Workshops

Sense has been raising awareness of rubella and MMR in a variety of ways. This has included working with New Link in Peterborough, an information service that works with asylum seekers/refugees and new migrants on issues such as health, education etc.

Workshops aimed at the Polish, Czech and Latvian communities were delivered and 73 people attended. The purpose of the workshops was to establish if the communities were aware of the effects of rubella and knew about the MMR vaccine, if so, had they had the vaccine and if they had not, what were the reasons for their choice. Of the 73 people who took part two were not registered with a GP, five were concerned about the safety of the vaccine, 21 who were parents had already had their children immunised with single vaccines in their country of birth and two felt that the vaccination was not necessary. The remaining 45 did not give a reason.

Leaflets

Information about rubella and MMR was put together in the form of leaflets in Czech, Latvian, Polish and Lithuanian by New Links in Peterborough, based on what the communities felt was important for them to know about rubella. This was in response to the questionnaires and workshops that they ran for Sense, as part of a consultation exercise to find out knowledge of rubella and MMR in the local community.
Sense and the Department of Health jointly produced an updated version of the rubella and MMR information in 2010 to replace the existing version of ‘rubella the facts’. It was felt that in order to engage with a range of communities rather than produce information in just English and put together word document versions of the same information in different languages, that leaflets in colour with appropriate cultural images that the communities could relate to would be far more suitable and effective for a wider audience. As an organisation Sense also felt that they did not have information in other languages. The leaflet which is entitled ‘thinking of getting pregnant’ highlights:

- What German measles are?
- When is someone infectious?
- When and how does it damage the child?
- Protecting your unborn baby- before your pregnancy, during your pregnancy and after you’ve had your baby

The leaflet is available on both Sense and the DH website. Copies of the leaflet were also distributed to local GP surgeries.

Audio information

In order to promote accessibility of information (particularly for people with low literacy levels and visual difficulties) audio translations in Bengali and Tamil (as these are the groups with the highest susceptibility) were put together for people to access on the Sense website as an alternative to just having written information.

Articles in community newspapers

In order to raise awareness of the issue of rubella and MMR, it was decided to target local media as a way of disseminating information across to susceptible groups. Articles were placed in the East London News and Janomot, two free local weekly community papers aimed at the Bengali community residing in the boroughs of Newham, Tower Hamlets, Hackney, Redbridge, Barking and Dagenham. The former aiming to target the 800,000 population residing in East London and the latter with a circulation of 20,000.
Contacting GP’s

23 GP surgeries were contacted within London with a view for Sense to work with them to increase awareness of rubella/MMR amongst ethnic minority groups within their relevant surgeries. The response was very poor and there was an unwillingness to take part; reasons included ‘we don’t record the ethnic group of our patients’ and one surgery claiming that they had no patients from ethnic minority groups at their surgery. Due to the poor response from the surgeries it was decided not to pursue this further.

Rubella and MMR talks

Local community groups in London were contacted and offered free awareness talks about rubella and MMR. This provided an opportunity to answer any questions or dispel any myths about rubella and MMR as well as raise the profile of the work that Sense carry out with deafblind children and adults.

Many groups had mixed responses about the relevance of the talks for their target audience e.g. older people, but still requested information to be sent to them on the topic for interest that they could pass on to their families. The Tamil Community Centre in Hounslow in Middlesex is a voluntary organisation which aims to provide the Tamil community with advice, information and support on issues such as health and well being. A talk about rubella and MMR was delivered to 45 people; which they found interesting. All of them had been vaccinated with MMR but they were interested to know the risk that it has not on the individual who has rubella but the harmful effects that it can have on the unborn child of a pregnant mother. They responded positively and have requested another talk to be delivered again after September.
Presentations

Presentations to immunisation coordinators about the importance of rubella and MMR were delivered.

Northwick Park hospital in North West London organise an annual infectious diseases study day aimed at health professionals including student nurses/midwives. Sense was invited to go and speak on the topic of rubella in 2010 and 2011. 70 people attended in 2010 and 80 people attended in 2011. The focus of the presentation in 2011 looked at what rubella is, the effects of rubella, control and decline of rubella, reported CRS (congenital rubella syndrome) births in England, Scotland and Wales 1991-2010, concern over MMR following the Wakefield studies, who is at risk of infection, when is the risk of infection, rubella susceptibility by ethnic group in North London, case studies of two CRS babies born at Northwick Park Hospital, protecting against rubella, MMR and when should it be given, the role of health professionals before, during and after pregnancy, myths about MMR and barriers to low uptake of the vaccination. The presentation was very well received and generated lots of positive interest, feedback and questions resulting in Sense having been invited back again to speak in 2012.

Sense was also invited to give a presentation at the DH vaccination and immunisation learning and dissemination event for the national support teams for vaccination and immunisation policy in London, between 90-100 guests attended the event. It was aimed at community health nurses, GPs etc, on the topic of exploring the factors that influence the uptake of immunisation amongst ethnic minority groups.
Findings

Questionnaires- Peterborough

98 questionnaires were completed by people in Peterborough (Latvians, Polish, Lithuanian, Slovaks, Czechs and Iraqis) with 51% being male. A number of questions were asked which included age, religion, if they had children, had they been vaccinated, if they had not been vaccinated what were the reasons for their choice. The majority of them were between the age range of 26-30 years old (23.5%), married (36.7%), Christian (71.3%) and 67% of them had children. The largest ethnic group were Polish (21.5%). The majority of the respondents had been in the UK less than 2 years (35.8%).

69% of Latvians had heard of MMR, with Lithuanians being the least informed group (5%). A significant number of them (44%) could not say what MMR protects them from, particularly the Polish. 65% did not hear about MMR in the UK and of those that did, it was largely from their health practitioners. 65% of them did not hear about MMR in their country or were not sure if they had. Of those who did, they were mainly Latvian/Russian. The Polish were the least informed about MMR while in their country.

27.4% did not answer what they thought were the medical complications associated with catching measles, mumps and rubella, with a significant percentage thinking that infertility and death were the complications. 70.4% thought that catching these diseases are very serious for mothers and children (72.5%). Similarly a significant majority thought that it is very important for mothers (79%) and children (81%) to be vaccinated against these diseases. When asked if they have been vaccinated with MMR or single vaccines it was largely the Polish, Slovaks and Czechs who received single vaccines in their own country and Iraqis who received MMR in their own country (44%).

With regard to immunisation information about their children, 49% of parents mentioned that they had vaccinated their children either with MMR or the single vaccine (mainly measles). Those who were vaccinated outside of the UK were represented by Russians, Latvians
and Polish (mainly single vaccines). Iraqi children were mainly vaccinated with MMR in the UK.

A significant percentage of the parents (33%) had one or more of the diseases compared to only 7% of their children. However, the majority of parents (35.8%) could not recall the history of their child’s immunisation. 86% of the parents said that they would definitely have their children or themselves vaccinated against MMR. Preferred sources of information about MMR were from health professionals, from friends, people in the community, newsletters/magazines in community languages and places of worship.

The data from this questionnaire revealed that the Latvians and Russians were comparatively well aware of rubella and MMR.

**Questionnaires- Nottingham**

279 questionnaires were completed in Nottingham. 93 were male and 186 were female aged between 16-46+ years of age. Zimbabwe, Pakistan and Poland were where the largest number of respondents had been born. Parents who were born in Pakistan had a significantly higher number of children born in the UK (46), followed by parents born in the UK (22) and then parents born in Ghana (19). This was consistent with the number of years that they had been in the UK. Of those that had children 17 were unsure as to whether their children had had the vaccine. 10 children had not been vaccinated with MMR and the majority (187) had had the vaccine, 65 of those that responded had no children at all.

Out of mumps, measles and rubella, eight children were reported to have had rubella. When asked if the vaccine was offered and would they have it 130 of them agreed that yes they would definitely have it, 41 said they would probably have it, 34 were unsure, four said they would probably not, 28 had already had the vaccine and the remaining 46 did not respond to that question. When asked if they would have their children vaccinated 96 said yes they definitely would, and four said they probably would not, 16 were unsure and 18 said they probably would, 90 of them did not respond and 55 of them had already had their children vaccinated.
In terms of how they would like to access information about rubella/MMR they agreed that the GP, leaflets in their own language, places of worship and the pharmacy would be where they would seek information. Some of the questions/comments the respondents had were that they were not aware about the side effects of the vaccine, or the symptoms and wanted to know more. What did MMR stand for? Was it dangerous and preventable, does it impact you in later life? Can it kill you?

There were almost 1/3 of the respondents that did not complete a response to what was an important question that was being asked about vaccination, so it is difficult to ascertain whether they would have responded positively to being vaccinated or the opposite.

Focus groups- Peterborough

Five focus groups were carried out in collaboration with New Link. 39 people from the Polish, Slovak/Czech, Lithuanian, Iraqi/Kurdish and Afghan communities participated. The Lithuanian, Afghan and Slovak/Czech groups had not heard of the MMR vaccine but had heard of them as single vaccines. The Afghan group had no idea what the MMR vaccine was for, yet the Iraqi and Kurdish groups although had heard of the vaccine were not quite sure what it was for. When asked about what the groups knew about mumps, measles and rubella it was only the Polish group that were aware of the symptoms of these diseases. Across all of the groups although the children had been vaccinated the parents were not aware of the names of the vaccines, which suggests that whilst there was not a reluctance to vaccinate, specific knowledge about what their children were being vaccinated for amongst the parents was poor.

In terms of who would decide whether the child should be immunised in the case of the Slovak/ Czech group it was usually the men as they were regarded as head of the family. The Iraqis/Kurds, Afghans and Polish would make a joint decision. Whereas the Lithuanian group agreed that the decision to vaccinate was always a family decision and would even include the grandparents. There was a general consensus that information about immunisation would be sought from GP’s, nurses, health visitors, leaflets and the internet. The groups largely agreed that in most cases both parents would go and get the
child immunised with the exception of the Polish group where it was usually the mother that would take the child for their immunisations.

When asked if there is anything that would prevent them from having either themselves or their children vaccinated with MMR they agreed that there was nothing with the exception of their child being unwell on the day of the vaccination, and the Polish group emphasising that negative media coverage linking MMR to other illnesses was not helpful. The Slovak/Czech group highlighted that they preferred the single vaccines as opposed to MMR which they felt could be too strong and not as effective. The Iraqi/Kurdish group did not feel that there was anything that would prevent them or their children from having the vaccine as they felt that MMR was necessary to reduce the risk of children getting ill. The Afghan group mutually agreed that they should have the vaccine for them and their children. When asked about where they would access information about MMR and where they would go to get it, all of the groups mentioned their GP as a source of information. The Afghan group said that they would also seek information from the hospital. The internet, leaflets, information from friends and New Links were all mentioned as sources of information about MMR.

The Slovak/Czech group wanted to know what the side effects of MMR were, how long it gives protection against mumps, measles and rubella and at what age to have it. The Iraqi/Kurdish group talked about MMR as a term that was used to describe the vaccine. The Polish group wanted clarification on the side effects of MMR, the Lithuanian group wanted more information on the symptoms of the illnesses and the Afghan group wanted to know what MMR stood for, the difference between mumps, measles and rubella and the role of rubella. When asked how the groups would prefer to receive information about MMR leaflets in their own language, information from the GP, health professionals, the Mosque, the community centre and in the Slovak/Czech group from family discussion were the preferred choices.

The focus group discussions provided qualitative data which revealed certain information that the questionnaires failed to provide, for e.g. the focus groups picked up concerns and anxiety that some people had with regards to whether MMR was too strong for the body to
cope with, and what the side effects of MMR were. The Lithuanian, Slovak and Polish groups were keen to find out more about MMR, which was difficult to deduce from the questionnaire. There was a clear consistency between the data from the questionnaires and focus groups about the ways in which people wanted to access MMR information.

There are a number of reasons why minority ethnicity migrants may be susceptible to rubella and at risk of catching rubella:

- They may have come from countries with no vaccine
- They may be from a country whereby the vaccine has recently been introduced or there is low vaccine coverage in that area
- They may have recently arrived in the UK and are less likely to have been vaccinated with MMR
- They live in communities where there may be dense populations of people in similar circumstances
- They may have come from a country where the vaccine schedules are very different to the UK
- They may have more than one child under the age of 5 resulting in multiple sometimes complex vaccination schedules to manage
- The mother may be pregnant already and travel back to her home country or conceive abroad where there may not be protection against rubella, which is particularly harmful to the unborn child during the early part of the pregnancy
- Rubella is not always symptomatic and the symptoms can quite often be attributed to other things e.g. rash
- They may not understand the risk that rubella has on the unborn child during the early stages of pregnancy and that two doses are needed for full protection from the virus
- They may have recently arrived in the UK and may not be registered with a GP
Conclusion/Recommendations

- Strategies need to be tailored to specific reason/s for low uptake e.g. a general leaflet indicating a vaccination schedule will not address doubts about the safety of the vaccine.
- Need to assess the source of the message about immunisation e.g. in some communities it may be more effective to target and work with community leaders who may act as the ‘gatekeepers’ they are quite often for some communities a trusted source for where information is received and disseminated.
- Need to acknowledge that some decisions about refusing immunisation opportunities are ‘informed’ but are based on obsolete information e.g. Wakefield case.
- Health professionals need to be prepared to address complex arguments against immunisation through comprehensive training and up to date information.
- It is important for health professionals to utilise opportunities to raise awareness about rubella and MMR following pregnancy but before discharge from hospital, particularly if the patient has not been immunised or have had a blood test which shows they are not immune e.g. if there is an opportunity for the first dose of MMR to be given in hospital before discharge rather than waiting to see the GP this should be utilised.
- Immunisation campaigns should provide information and the opportunity to be immunised for young people and women pre-pregnancy for e.g. MMR status could be checked at the point HPV vaccine is offered and administered as appropriate.
- Health professionals own experience or views about immunisation can impact their willingness to advocate for their patients to be immunised which they need to be aware of.
- A universal one size fits all approach is not the most effective way to raise awareness about rubella and MMR, approaches should be tailored to the specific needs of the community in order to ensure maximum impact, ensuring cultural sensitivity and appropriateness of images that are used, and respect of cultural and religious beliefs e.g. one manufacturer of the vaccine uses pork gelatine which would therefore conflict with the religious beliefs of Muslims.
Opportunities to answer concerns of the parents before they or their child is vaccinated should be provided so that parents can make informed choices about vaccination.

Relevant and up to date information needs to be provided to communities to dispel any myths or concerns about rubella and MMR vaccination (this needs to include information that can be accessed through websites, leaflets and other channels).

Parents and children who may have settled into the UK from abroad may have arrived from countries that have low vaccine coverage and not be aware of the risks and symptoms of how rubella can be passed on to pregnant women, in addition to being unaware of the vaccination schedules of the UK, as part of their entry into the UK, migrant families should have their immunisation history checked and be offered the MMR vaccine as appropriate, at the earliest possible opportunity.

Service providers and policy makers should have access to accurate, robust and useful data to identify the at-risk populations and working in partnership with the voluntary sector can help to achieve this.

As there is no national programme to ensure follow up for women who have been identified as susceptible, these women could pose a potential risk to future expectant mothers.

Partnership working between the statutory and voluntary sector can help to utilise opportunities and resources and avoid duplication particularly during challenging financial times.

MMR uptake rates are at their highest for 13 years, there is 90% coverage in much of the UK and a very few cases are reported each year, however there is still a cohort of unvaccinated women whom are now reaching adulthood that could pose a potential risk of another outbreak and this needs to be addressed.

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References


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