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# Tailoring Immunisation Programmes Charedi community, north London

Implementation of the WHO's Tailoring Immunisation Programmes (TIP)

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# Abbreviations

CCG: NHS Clinical Commissioning Group

GP: General Practitioner

HPT: Health Protection Team. Refers here to the North East and North Central London HPT

LSOA: Lower super output areas

MMR: Measles, mumps and rubella (immunisation)

NHS: National Health Service

PHE: Public Health England

TFR: Total Fertility Rate

VPD: Vaccine-preventable disease

## Executive summary

Public Health England (PHE) is the expert national public health agency which fulfils the Secretary of State for Health's statutory duty to protect health and address health inequalities, and executes the Secretary of State's power to promote the health and wellbeing of the nation.

PHE's first function is to protect the public's health from infectious diseases and other public health hazards, working with the NHS, local government and other key partners both national and internationally. This includes providing the national infrastructure for health protection, evaluating the effectiveness of immunisation programmes, procuring and supplying vaccines, and providing expert advice and guidance to commissioners and providers.

In England, the right to receive recommended vaccinations is set out in the *NHS Constitution* originally published in 2009, and updated most recently in 2013. There is a statutory duty on the Secretary of State for Health to ensure, that any recommendation from the Joint Committee on Vaccination and Immunisation (JCVI) for a new or changed national immunisation programme is implemented. In such cases, DH is responsible for policy and funding and PHE, in collaboration with NHS England, implements the programme.

The monitoring of and response to notifications of vaccine preventable diseases (VPDs) across north east and north central London is the responsibility of the north east and north central London health protection team (HPT). This is a local office of PHE.

NHS England is responsible for commissioning the local provision of immunisation services and the delivery of new programmes. General practices deliver the majority of the infant immunisation programme but increasingly other providers have been commissioned to deliver immunisation services for older children including specific immunisation teams and school nursing services.

As part of efforts to eliminate measles and rubella, the World Health Organisation Regional Office for Europe (WHO/Europe) developed the *Tailoring Immunization Programmes* (TIP) method and tools to identify susceptible populations, determine barriers to vaccination and implement evidence-based interventions. The approach draws on health programme planning models, including the medical humanities, the social and behavioural sciences.

The TIP methodology was implemented in north London, within the Charedi community, a community in which sub-optimal immunisation coverage is known to result in persistent outbreaks of vaccine preventable diseases (VPDs). This report covers a review of current literature and four sub-studies (epidemiological analyses, a service evaluation and a community questionnaire), culminating in recommendations to inform the tailoring of immunisation services for this community.

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# Background

## The Charedi community, north London

The Charedi are a community of strictly observant Orthodox Jews. The movement began in Poland in the 17<sup>th</sup> century and spread throughout Eastern Europe. Hackney is home to one of the largest Charedi Orthodox Jewish communities outside New York and Israel. The community was established in Stamford Hill in the 1920s, growing significantly during the Second World War as new arrivals fled the Holocaust<sup>2</sup>.

A 2011 study in Hackney identified that the community comprised 7% (17,587) of the population of the borough, and 17% of children aged 0-14 years<sup>3</sup>. The adjoining borough of Haringey was estimated to have approximately 2,844 Charedi residents in 2013<sup>4</sup>. The neighbouring borough of Barnet is home to the highest proportion of Jewish residents in England, however, only a small proportion are known members of the Charedi community<sup>5</sup>.

A recent population report of the British strictly Orthodox Jewish community describes it having 'extraordinary demographic growth'<sup>6</sup>. The report estimated a total fertility rate (TFR) of 7.0, meaning that the average number of children born to a strictly-Orthodox Jewish woman is 7. This compares to the TFR of the total population of England and Wales of 1.93. The Charedi population has a high number of children and average household sizes are much larger than the Hackney average. The projected population increases have significant on-going implications for the needs of the community.

## Immunisation uptake in the community

Since April 2013, childhood immunisations in England have been commissioned by NHS England. Infant and pre-school immunisations are generally delivered through General Practice.

Recurrent outbreaks of VPDs in the north London Charedi community indicate sub-optimal immunisation coverage. Membership of the Charedi community is not captured on any routine health records but general practices in areas with high proportions of Jewish patients report lower immunisation coverage. In 2011 three GP practices in the north of Hackney reported having 41-78% Jewish patients<sup>7</sup>. Immunisation uptake in practices located in north Hackney and therefore likely to serve the Charedi community are generally lower than in practices serving the rest of the population. Across the borough border in Haringey, a 2013 Health Equity Audit regarding childhood immunisation in 2011-2012 noted similar uptakes across all ethnic groups with the exception of those residents identifying themselves as being Jewish<sup>8</sup>. There was a significantly lower uptake in children (across all vaccination targets) identified as Jewish living in the south of Haringey<sup>9</sup>.

Studies within Orthodox Jewish communities in other countries have also indicated lower coverage in comparison to the non-Orthodox Jewish population, such as in Antwerp, Belgium where a four-fold lower chance of complete vaccination was identified in children

from the community<sup>10</sup>. In the absence of accurate community specific coverage data in the UK, the recurrent outbreaks of vaccine preventable diseases suggest sub-optimal coverage.

## Tailoring Immunisation Programmes for under-served communities

Suboptimal vaccination coverage threatens to jeopardise progress towards disease elimination and allow VPDs to re-emerge in the European Region.

WHO/Europe developed the Guide to Tailoring Immunization Programmes (TIP) to assist health care professionals, public health authorities and decision-makers better diagnose the factors influencing vaccination intentions, decisions and behaviours to enable tailoring of services to optimise uptake in under-served communities.

The TIP approach helps immunisation programme teams to:

- identify populations susceptible to VPDs
- diagnose supply- and demand-side barriers and motivators to vaccination
- recommend evidence-informed responses to sustain vaccination.

### TIP Approach step by step



## Using the TIP approach within the London Charedi community

### The formative phase. Identify and diagnose

#### Part1: Defining the research problem

To help define the research problem the following activities were carried out:

- current immunisation service support within the community was mapped
- a literature review was undertaken
- relevant surveillance and outbreak data was examined
- stakeholder meetings were held

### Support for immunisation services in the Charedi community

In the London borough of Hackney, the six general practices in the north of the borough providing services to the Charedi community have been supported by the Homerton University Hospital NHS Foundation Trust. Various models of immunisation delivery were provided to supplement immunisation through general practice. This included the introduction of community immunisation clinics, the employment of a Charedi outreach nurse, home immunisation (restricted) and school based clinics during a measles outbreak. Health visiting teams also provided significant input to the pre-school immunisation programme. In addition to discussing immunisation with parents, it was estimated that they delivered one third of immunisations with a particular focus in the North of the Borough where the Charedi community reside<sup>11</sup>. In October 2015 the commissioning of the Health Visiting Service in the borough transferred to the London Borough of Hackney so Health Visitors are no longer immunising or supporting call/re-call of patients.

Other measures to support and promote immunisation in the community included providing Information on childhood immunisations and vaccine preventable diseases in Hebrew and Yiddish. Health columns and adverts in local Jewish press have also been used to promote immunisation and advertise local immunisation clinics. A number of these initiatives were short term projects and funding was not available at the end of the project. Additionally some initiatives were not fully evaluated and evidence of their effectiveness was not available.

### Literature review

A literature review was carried out (Appendix 1) to describe the burden of vaccine preventable disease and identify factors that may impact on immunisation coverage within the community. A summary of findings is provided below

#### Factors associated with immunisation coverage

Only limited UK-based data is available but this alongside international research in other ultra-orthodox Jewish communities suggests that uptake is influenced by factors including:

**Birth order:** a child's birth order was inversely related to vaccination status, the more children a family has, the less likely they are to be fully vaccinated. This is thought to be due to issues such as;

- increased time pressures with larger families
- mothers with larger families were more likely to refuse new vaccinations as their older children had not had them and had not become ill. This led to the mistaken belief that they were not needed.

**Health beliefs:** Studies have been inconsistent on the impact of health beliefs in the Charedi community. A 2011 Israeli study identified birth order (having >6 siblings), higher levels of maternal education, parental religious beliefs against vaccination, perceived risk of VPDs being low and a mistrust of the Ministry of Health as factors having a negative impact on immunisation uptake<sup>12</sup>.

**Access to immunisations:** problems with access to health or specific immunisation services as a barrier is consistently highlighted in the literature. Access is affected by the number of children within the family unit (reducing parental time) and availability of services.

## Vaccine preventable diseases

Multiple outbreaks of vaccine-preventable diseases (e.g. measles and mumps) within Orthodox and Ultra-Orthodox Jewish communities across the world have been reported<sup>12-18</sup>. A measles outbreak in 2004 in Jerusalem resulted in 117 cases, including eight hospitalisations and one death in a child with an underlying lung disease<sup>19</sup>. The number of outbreaks, recurrence and their size indicate inadequate vaccination coverage, and their confinement, illustrates a significant degree of social segregation. International travel increases the risk of disease importation to the London community, and vice versa, to other Charedi communities throughout the globe

## Outbreaks in North East London

Within the London community, the following clusters and outbreaks have been detected over the last 10 years:

**Measles:** The most recent measles outbreak in 2012/13 resulted in 156 notifications of measles, predominately in children aged between 1 and 4 years. PHE were notified of 10 children taken to hospital with suspected measles, of which 5 were admitted for at least one night. There are likely to have been others.

**Mumps:** 144 cases of mumps in the community notified between 1998 and 1999. Half of all cases not immunised. Links to possible importation from Belgium and Israel.

**Hepatitis A:** 5 cases of hepatitis A were reported in 2010, of which 2 were travel-related (Jerusalem) and 3 were secondary cases. This resulted in emergency immunisation of **900** community members.

**Pertussis (whooping cough):** During the summer of 2015, two household outbreaks of pertussis in Charedi families in Hackney were notified. Both outbreaks included infection in infants whose mothers were not vaccinated antenatally against pertussis (as recommended nationally).



There are recurrent outbreaks of vaccine preventable disease within the North East London Charedi community. These are likely to be due to a lower than average immunisation uptake within the population. The reason(s) for the low uptake are unclear and there is little recent evidence about knowledge, attitudes and practices relating to immunisation, and the impact of service delivery upon uptake. The TIP approach aims to diagnose supply and demand side barriers and motivators to immunisations, and to provide evidence-informed recommendations to optimise immunisation coverage, for those commissioning and providing local programmes.

### Stakeholder Meeting (April 2014)

A multi-agency meeting, hosted by PHE was held in London to inform local stakeholders of the TIP tool, offer examples of where this has been implemented within Europe and discuss implementing this locally with the Charedi community. The meeting was attended by representatives from WHO Europe, NHS England, and the London borough of Hackney Public Health Department, the Homerton University Hospital NHS Foundation Trust, and a local Rabbi with a responsibility for health and PHE (health protection and behavioural insights directorates).

It was agreed that this could be a very useful approach within the north London Charedi community, providing commissioners, providers and service users up to date information on the demand and supply-side barriers to childhood immunisation, and recommendations for providing an evidence-informed response.

### Partners Meeting (July 2014)

A day-long local meeting was held in Stamford Hill, Hackney to introduce key health and community leads to the TIP model. The meeting was attended by community representatives from three local children's centres, Homerton University Hospital NHS Foundation Trust providers, NHS England, a local Rabbi with responsibility for health, a general practice manager, the health policy lead for the Interlink Foundation (umbrella organisation for Orthodox Jewish charities and voluntary organisations) and WHO Europe.

The aims of the meeting were to:

- Provide participants with an overview of TIP
- Identify the strengths, weaknesses, opportunities and threats relating to immunisations and the current programme for the local community.
- Seek participants' experience and knowledge to set the scene as this piece of work progresses.

### Partners Meeting: Discussion

The community has 85 synagogues in the borough of Hackney, with the Charedi comprising over 50 different streams. As such, it was stressed that there are very different

cultures and beliefs within the Charedi community. It was felt that this strong, distinct and growing community is very under-represented in the public sphere.

It was noted that the community has a high population growth rate. Approximately 25 babies are born into the community each week, resulting in a 4% net population growth year on year, with the community doubling in size every 15 years. Participants cited access to services as the largest factor to sub-optimal immunisation coverage. It was felt that a few years ago health beliefs (fears or concerns about vaccine safety, efficacy etc.) would have also been a strong factor, but more recently there has been a shift with increasing acceptance, though perhaps still some concern particularly regarding the MMR vaccine and fears regarding autism. It was noted that the Rabbinate has become willing to discuss childhood immunisations over the last couple of years, which is a significant shift and opportunity. Vaccine delay of infants was acknowledged to be a challenge, with some families preferring to hold all vaccines until their child reaches around two years of age.

Some mothers were noted to be anxious of their children receiving too many immunisations in one appointment, wanting to split the immunisations over two or more appointments. Homeopathy was also noted to be popular with a small proportion of families as an alternative to immunisation.

Communication of health promotion messages was noted to be a challenge since many families are without televisions or the internet at home. As such, it can be difficult to get timely messages to the community or quash any mis-information.

Participants felt that TIP would be useful and applicable to the community given the context of recurrent outbreaks and poor immunisation coverage. As such, the outcomes of the meeting are given below, with the SWOT analysis illustrated in Figure 2 and discussion outcomes about local implementation of TIP and associated next steps below.

## Partners Meeting: SWOT Analysis

**Table 1.** SWOT analysis of the local immunisation programme (conducted by participants at the Partners Meeting, July 2014)

Strengths of the local immunisation programme	Weakness of the local immunisation programme
Immunisation clinics in three children’s centres: Convenient times and family-friendly facilities, resulting in a good patient experience. Friday afternoon summer clinics Sunday monthly clinics (Lubavitch) Wednesday weekly clinic (Norwood) Immuniser from the community and other staff who have a positive attitude towards the community. Free immunisations Universally available	Current facilities at GP practices reported to give poor patient experience: Long waiting times and poor family friendly facilities (e.g. no toys and not enough space for buggies). Not enough immunisers to meet potential demand Not enough admin support to enable systematic call/recall with follow up of non-responders  Reported difficulties in getting appointments for those who want to vaccinate their child Traditional communication methods unsuitable

<p>Willingness of the community and professional stakeholders to work collaboratively in identifying and overcoming immunisation barriers.</p> <p>Significant enthusiasm within the community to improve immunisation uptake.</p> <p>Contacting families who don't, or delay immunisations and discussing concerns with them appears to change some beliefs and behaviours. It was noted that this was only successful with sufficient time and cultural understanding.</p>	<p>e.g. internet, text messages, press</p> <p>Insufficient cultural awareness training for immunisation staff</p> <p>Inadequate resources when taking into account the unique characteristics of the community e.g. larger families, younger population, cultural and religious practices</p> <p>No or little access to school aged immunisations from the school nursing service</p> <p>Lack of any provision to encourage fathers to attend vaccination clinics</p> <p>Some members felt the community felt "attacked" by professionals on the issue of immunisation.</p> <p>Too many presumptions as to what the community want and don't want regarding health services.</p> <p>Innovative solutions often not sustained</p>
<p><b>Opportunities of the local immunisation programme</b></p>	<p><b>Threats to the local immunisation programme</b></p>
<p>Extension of children centre immunisation provision e.g. after school 4-6 Mon-Wed</p> <p>Summer schemes</p> <p>Community specific communications e.g. use of community pharmacists (who are administering vitamins, etc. already to families)</p> <p>Service development e.g. more father friendly clinics</p> <p>To use local advertising through free weekly newsheets</p> <p>To work in school with young women who will be future mums</p> <p>Consider creating "community champions" for immunisations.</p>	<p>Sustainability/funding for expansion of targeted services</p> <p>Vaccine myths are still prevalent in the community e.g. MMR</p> <p>Very close knit community making it difficult to spread positive messages about immunisations</p> <p>Closed community</p> <p>Resource constraints to expand and run bespoke clinics</p> <p>Potential change of political climate</p>

**Partners Meeting: Outcomes**

The day-long meeting culminated in a series of issues and suggestions which fed into the initial problem statement (table 2) and situation analysis (table 3) for the TIP approach in the Charedi community.

<p><b>TIP initial problem statement – North East London 2014</b></p>	
<p><b>What is happening?</b></p>	<p>Recurrent outbreaks of VPDs including measles and pertussis within the Charedi community in North East London.</p>
<p><b>Who does it affect?</b></p>	<p>Un- or under-vaccinated children within the Charedi community</p>
<p><b>What are the primary effects of the problem?</b></p>	<p>The most recent measles outbreak in 2012/13 resulted in 156 notifications of measles, predominately in children aged between 1 and 4 years. The outbreak resulted in several admissions</p>

to hospital

***What are the possible causes?***

Large family size leading to competing priorities. Poor access and lack of child friendly facilities, not enough immunisers to meet demand of large number of children within the community, vaccine safety concerns. Closed community with little access to national media, vaccine scares take a long time to dispel

**Table 2:** TIP initial problem statement

<b>TIP situation summary – North East London</b>	
<b>Problem</b>	Low immunisation uptake among the Charedi Orthodox Jewish community in North East London
<b>Potential primary beneficiaries</b>	Un- and under-vaccinated children aged 4 years and under.
<b>Key challenges</b>	
<b>Access to immunisation</b>	<p>Due to the high proportion of children within the community, is current immunisation service provision sufficient?</p> <p>How do general practice services compare to those in the community?</p> <p>How could services be improved to further meet the needs of the community?</p> <p>What do the Charedi community think of immunisation services and how would they like to see them improved?</p> <p>Competing priorities lead to missed vaccinations.</p>
<b>Communication</b>	<p>Do parents know what vaccinations their children should have?</p> <p>Lack of access to national information campaigns means positive messages slower to spread.</p> <p>Negative messages can stay longer within the close knit community</p> <p>How to 'normalise' vaccination and increase it as a priority?</p> <p>Worries and misconceptions about side-effects</p>
<b>Data</b>	<p>What data are available to confirm sub optimal immunisation uptake and the potential for further outbreaks of VPD within the Charedi community?</p> <p>Are there adequate call/recall systems in place? Are children whose parents delay vaccination given further vaccination opportunities?</p> <p>Do details of vaccinations given outside general practice e.g. community clinics get fed back to practices in a timely way?</p>
<b>Segmentation</b>	<p>What can we learn about families that immunise according to schedule and those who delay or refuse immunisations</p>
<b>Opportunities</b>	
<b>Community engagement</b>	<p>Continue to build on relationships already developed with community members and religious leaders.</p> <p>Explore opportunities to utilise community communication channels</p>
<b>Community specific services</b>	<p>Investigate the potential for increasing community specific services e.g. immunisation services on Sundays, more sessions in community venues</p>

**Table 3:** TIP situation summary

## Part 2. Stratify and prioritise target groups

The second part of the formative phase consisted of

- further analysis of surveillance and outbreak data
- a questionnaire survey of Charedi parents
- in depth interviews with parents and key informants

### What did the data show?

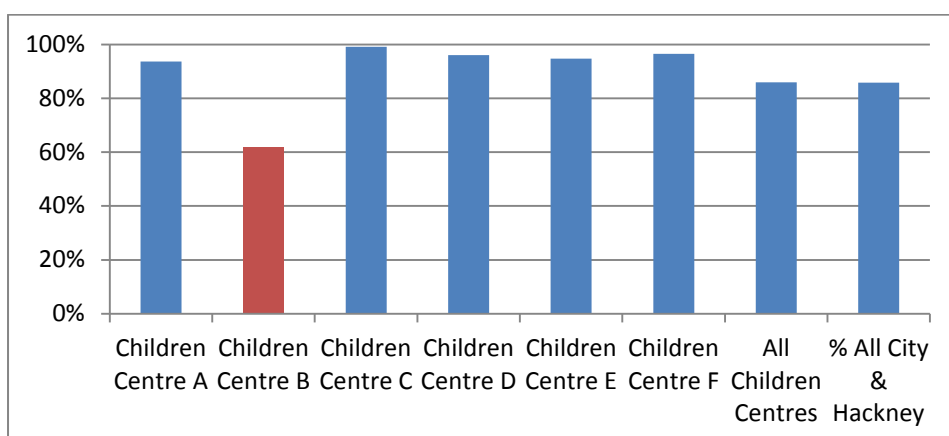
Data analyses were carried out to confirm the sub-optimal immunisation uptake and potential for further outbreaks of VPDs. General Practice provision for the Charedi community was also investigated. Details of the methods used are provided in Appendix 2.

### Immunisation Uptake

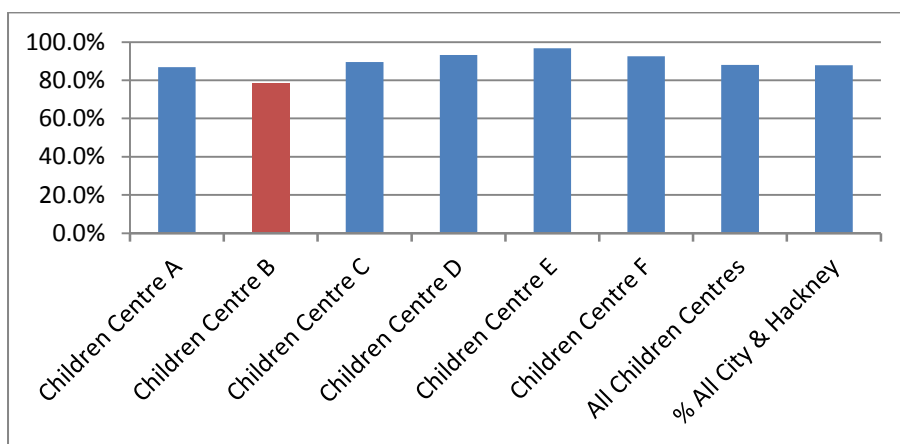
The immunisation provider at the Homerton University Hospital NHS Foundation Trust analysed immunisation uptake data of children according to the geographical location of their practice. GP practices are grouped to show their children centre association, of which there are six spaced across the London borough.

### Children’s centre B represents the area where most of the Charedi community live

Although uptake of children’s immunisations has increased within Hackney over recent years, rates within the north of the borough are markedly lower than that of the rest of the borough, (Graph 1) shows coverage of the 5 in 1 vaccine by 1 year of age by children centre areas. Uptake at 12 months in all areas except area B is above 90%, whereas in area B it is only 61.9%). For MMR at 2 years the borough has a rate of 86% compared to only 78% in children’s centre B (Graph 2).



**Graph 1:** Coverage of the 5-in-1 vaccinations, by 1 year, in the London borough of Hackney, according to Children Centre area (quarter 4, 2014-2015)



**Graph 2:** Coverage of the MMR vaccination by 2 years of age, in the London borough of Hackney, according to Children Centre area (quarter 4, 2014-2015)

### Burden of vaccine preventable diseases:

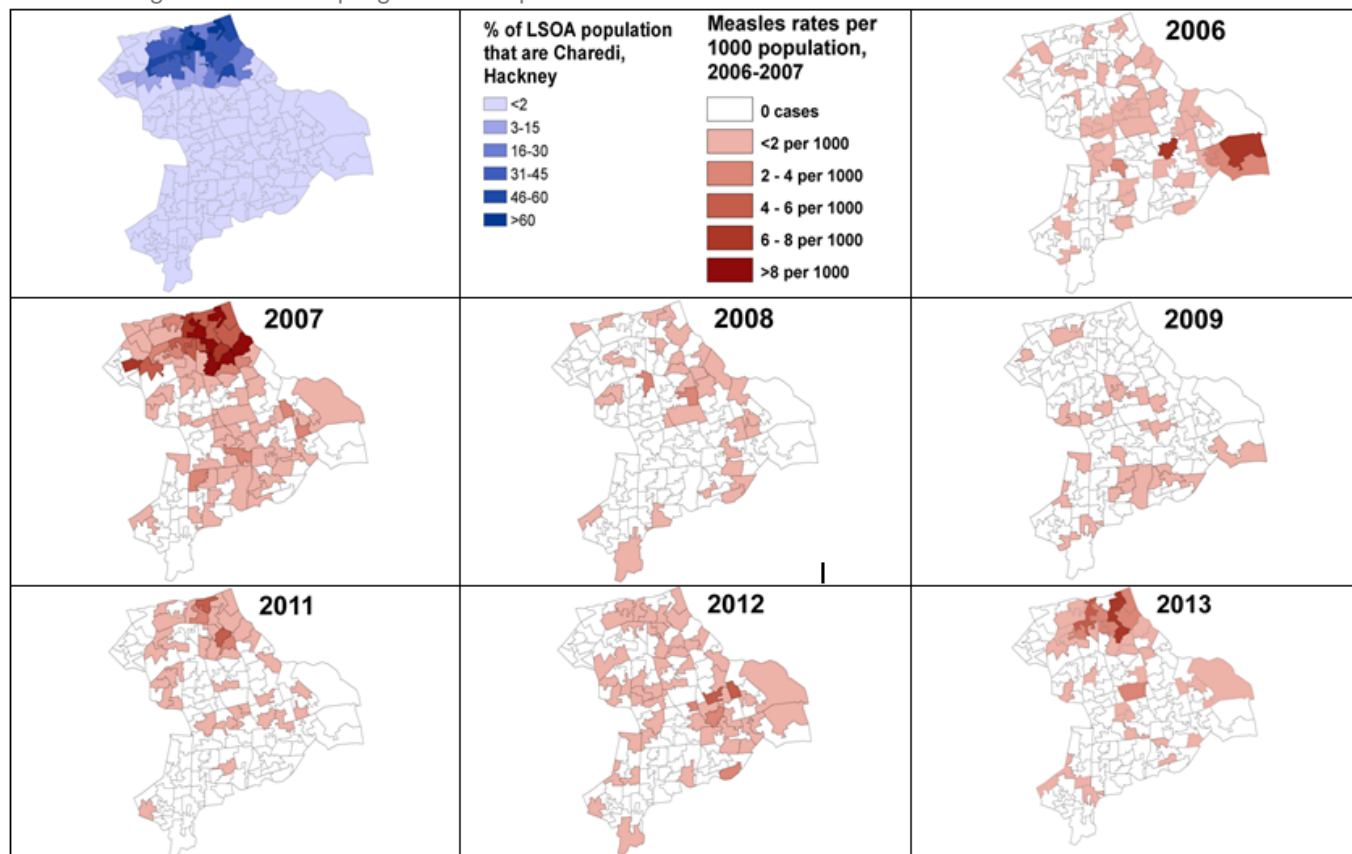
Data on measles cases in residents in Hackney was extracted from two databases used by the HPT between 2010-2013. Overall rates per year were calculated using an estimate of the proportion of the Hackney population that is likely to belong to the Charedi community as shown in a Local Authority report<sup>3</sup>. Maps were produced illustrating measles cases and population distribution. Methods detailed in Appendix 3

### Prevalence of vaccine-preventable diseases in the community

For the period 2006 - 2013 a total of 664 cases of probable and confirmed measles in Hackney were notified. The overall measles rate was calculated according to whether a case was likely to belong to the Charedi community or not. The rate of measles for the Charedi community between 2006 and 2013 was 117 per 100,000 population compared to a rate of 29 per 100,000 for the rest of Hackney.

### Geographical distribution of measles within Hackney (2006 – 2013):

The maps below illustrate the disproportionate burden of measles in Hackney within the north of the borough, where the Charedi community are focussed, and in some years, to the east of the borough, where a Traveller community resided.



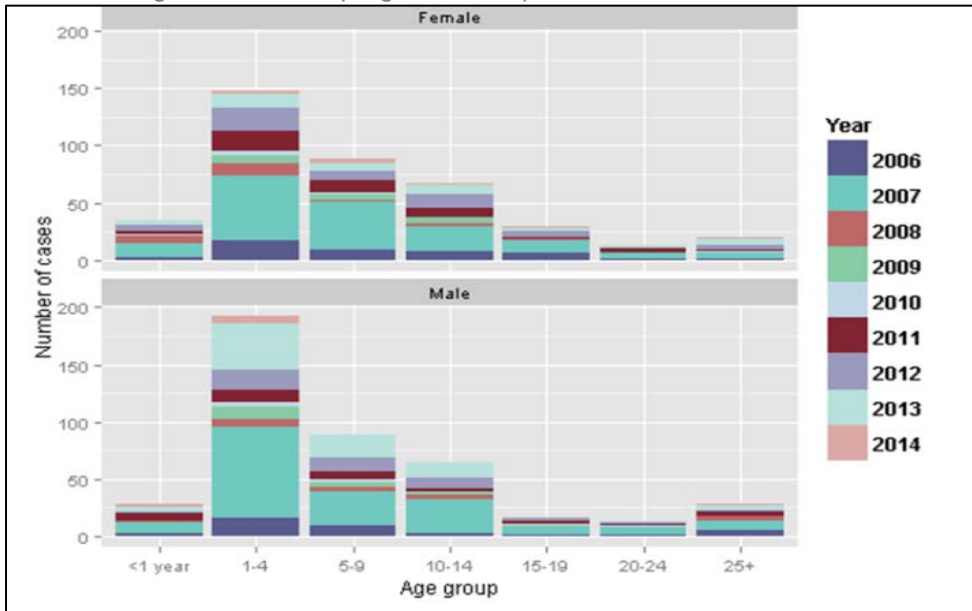
**Map 1:** Proportion of the population that are likely to be Charedi by LSOA (in blue) and measles rates per 1000 population by LSOA and year, London borough of Hackney 2006 to 2013; 2010 not included due to small numbers)

### Measles outbreak (2012-2013)

The last measles outbreak in the Charedi community took place between December 2012 and August 2013, resulting in 143 notified cases of which 91 (58%) were microbiologically confirmed, 39 (27%) were considered probable and 13 (9%) possible. More than 15 children who contracted the infection were taken to hospital, with at least 5 admitted for at least one night. Clusters and outbreaks were detected within households, crèches, nurseries, schools and at a youth camp.

Cases were largely reported in 1-4 year olds (see Graph 3), an age group in which children should have received at least one MMR vaccination.





**Graph 3:** Cases of measles, by gender, age group and year of notification, London borough of Hackney (2006 – 2014)

### What is known about those families reluctant to immunise children?

An analysis was conducted on measles cases and contacts from an outbreak in the Charedi community, north London, during 2012/2013 details in appendix 4. Reasons for low uptake of MMR vaccination amongst the families of cases, was explored using data captured during conversations with the cases and their families as part of case management by the HPT. Of the 94 families who had cases of measles during this outbreak, 21 families (accounting for 56 cases) were, and 4 were possibly reluctant to vaccinate, based on information they provided at the time.

For these families, reasons for reluctance to vaccinate was available for around half the cases. Nine families were concerned about the safety of the vaccine or did not believe its effectiveness or preferred “natural infection”.

Although the numbers are small, our data suggests a similar pattern to that reported in literature. As the birth order increases (i.e. the younger the child in the family) the general trend is towards a reduction in the percentage of children of that birth order that are fully immunised.

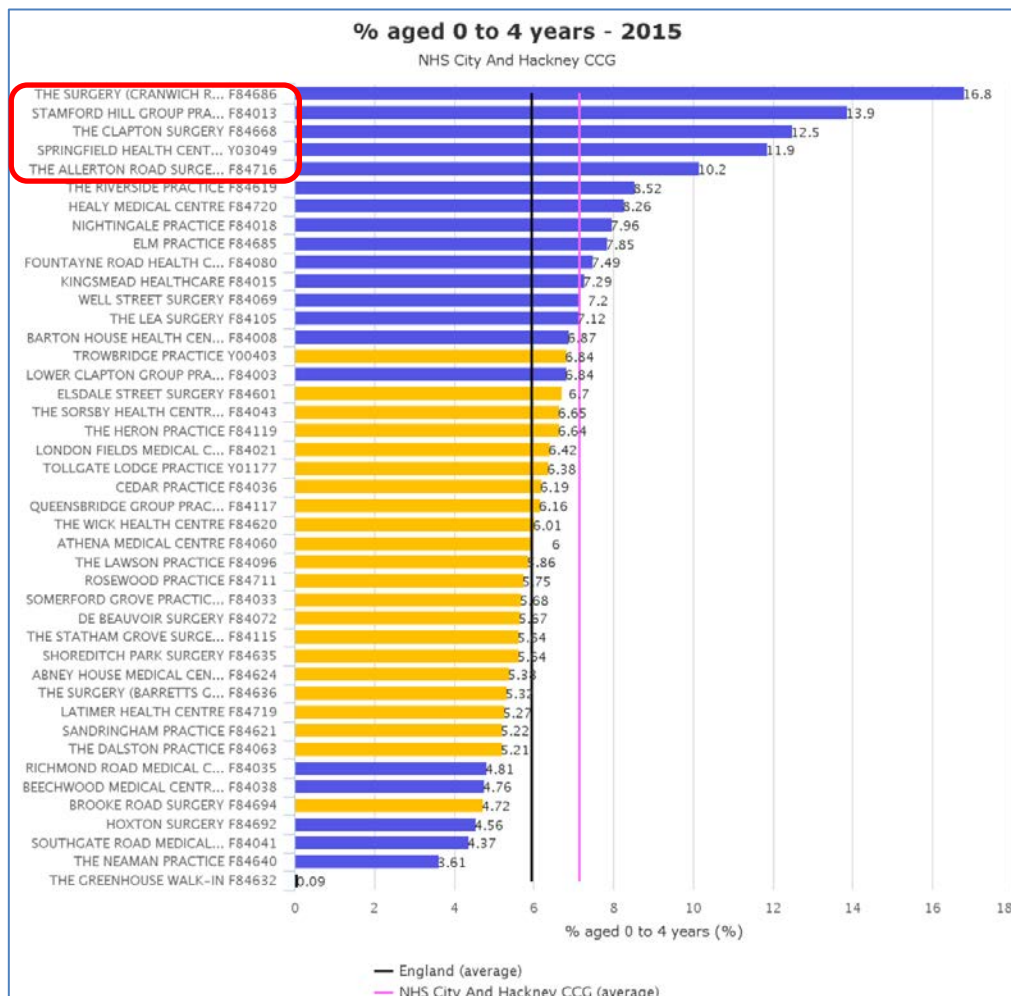
Parents whose children were not up to date with their vaccinations but did not hold negative beliefs about vaccination (50 families, 53 cases) sometimes were unaware of their children’s immunisation status. Parents also cited lack of time, particularly due to large families.

Some parents did not believe measles infection to be serious demonstrated by lack of vaccination of cases in this outbreak despite previous history of infection in siblings in previous outbreaks and a reluctance to vaccinate unprotected siblings during this outbreak.

### Are general practices able to meet the immunisation needs of the community?

PHE practice profile data<sup>22</sup> illustrates the high proportion of children (0-4 years) registered at the key GP surgeries (highlighted in red) serving the Charedi community (graph 4), which is around double the average in England (12%). The practices with blue bars have a

significantly different proportion of 0-4 year olds compared to the England average, and the yellow bars indicate no significant difference. The chart suggests that children’s services in these GP surgeries will be in high demand.



Graph 4: Proportion of registered patients aged 0-4 years in GP surgeries in City and Hackney Clinical Commissioning Group

**Data analysis confirmed that:**

- uptake of immunisations was lower within the Charedi community.
- recurring vaccine preventable diseases were placing a burden on the community particularly in children under 4years of age who should be protected by the routine childhood vaccination schedule.
- General practice services were potentially under pressure to provide immunisation services due to the high number of children in the community

## Parental Survey

To explore reasons for lower immunisation uptake and find out what would improve the immunisation experience for parents/carers a questionnaire survey was undertaken (Appendix 6) using the SWOT analysis as a guide. Stakeholders and community members including the lead rabbi were consulted. Parents were also asked to provide their contact details if they were interested in being involved in a qualitative interview study. Details of methods and results are contained in Appendix 7.

### What did parents think would improve their immunisation experience?

- **shorter waiting times** this was the most popular option with around 70% of respondents reporting this as helpful or very helpful.
- **child friendlier services** (64%)
- **more immunisation sessions run in children's centres** (60%).
- **Sunday appointments** (58%) and
- **home visits** (54%)

### Where do parents go for advice?

GPs were cited by over half of all parents as the most popular source of immunisation advice. Children's centres were mentioned by almost a third of parents whose children were up to date with their immunisations but just 12% of those whose children were not up-to-date. Despite their immunisation role in the community health visitors were only mentioned as a source of advice by less than 10% of parents.

### How satisfied are parents with the advice provided?

More than half of all parents / carers are not satisfied with the immunisation information available to them. This is considerably higher than the general population where in a recent survey of parental attitudes to immunisation commissioned by PHE (ref) only around 10% of parents were dissatisfied with the information they were provided.

### How could immunisation information provision be improved?

Having more information on benefits and risks of immunisation, community champions for immunisations and having a Charedi nurse were all considered helpful.

### What did the survey highlight?

- reducing waiting times and increasing child-friendly facilities are important.
- children's centres are popular as additional immunisation venues
- community specific initiatives such as Sunday clinics and Charedi nurse immunisers are also popular
- there are un-met Information needs within the community

### Part 3 Analyse behavioural patterns

The issues impacting on immunisation uptake highlighted from the work undertaken was analysed to explore behavioural patterns. The issues were grouped according to whether they were environmental, social/community or individual. Parents were grouped according to their beliefs/behaviours to ensure solutions can be tailored to meet the needs of different sections of the community.

**Table 4: Enablers and barriers impacting immunization uptake within the Charedi community**

Society level: Opportunity	Community level: Support	Individual level: Personal motivation
National Immunisation Programme Provided free mainly through GMP.	No evidence of systemic anti vaccine beliefs within the community.	GPs a popular source of info.
Good experiences with easy access, flexible services. E.g. out of hours, close by, walk in services.	Religious leaders support Immunisation.	Some parents report positive experiences of community specific initiatives e.g. clinics within childrens’ centres.
Appreciation of the non-mandatory system.	Openness to religious/cultural appeal/sensitivity. E.g. person from a similar culture, religious-based guidance/info materials.	Request for more information/knowledge about flexible appointment opportunities.
Previous initiatives to support immunisation in the community with positive outcome.	Openness to religious messages, advocates and communication channels to increase support for immunisation.	Wish to protect one’s child from diseases.
		Request for easy planning and being reminded.
		Most parents do have children immunised according to schedule.
Busy clinics: GPs have up to three times the proportion of 0-4 year olds (resource intensive).	Immunization not considered a social norm (a must-do in the community).	Safety concerns and misconceptions. E.g. MMR-autism, preferring to wait until child is older and multiple antigens.
Complicated appointment systems	Uptake historically lower than average.	Indications that caretakers may not be fully aware of child’s immunization status.
No space for buggies, lack of child friendly facilities, long waiting times.	Regular outbreaks of VPDs within the community.	Diseases not considered serious.
Inconsistent call and recall system: Missed vaccination due to childhood illness – not rebooked.	Large households weighted towards young children.	Competing priorities. Family commitments make finding time for immunisation difficult. Large family size. Birth order.
Series of reorganisations and service cuts within NHS and PH organisations putting services at risk.		Negative experience; e.g. of long waiting times and lack of child friendly facilities.
GMPs generally under increasing pressure.		Some parents believe better to delay immunisation until immune system better developed.
		Others missed appointments due to child being unwell on the day—not re-booked.
		Some parents report mis-trust of immunisation information provided.




# The Planning phase, design evidence informed responses

## Part 4 & 5 Define strategic priorities

### Feedback Meeting

A feedback meeting including community members, a senior Rabbi, NHS commissioners and providers, general practice staff, PHE,WHO, Government was held to discuss the findings and to input into the development of the recommendations. Participants were asked to suggest and prioritise solutions to address the issues of convenience, confidence and complacency highlighted by the TIP approach. The suggested priorities are detailed in table 5 below

Table 5: Output from stakeholder feedback meeting – suggested interventions

	Do now
	Short-term suggestions
	Mid-long term suggestions

Society level: Opportunity	Community level: Support	Individual level: Personal motivation
Provide clinics to suit community e.g. summer Fridays, Sundays	Continue and increase Charedi immunisation coordinators/outreach nurses	GP systems, set up regular call and re-call if not already set-up
Plan immunisation around community calendar	Community champions	Use immunisation reminder tools eg fridge magnets, wall calendars, leaflets, cards
Opportunistic immunisations e.g. child in for something else, siblings in with younger child	Engagement of religious leaders	Tailor messages to highlight seriousness of VPD. Hard hitting messages and facts??
Address waiting times	Community leaders education, community relevant health education	Develop consistent messages for all to communicate when they come in contact with parents
Home visits, out of hours, sessions in children's centres	Work with CCGs to increase engagement around immunisation	
Services not being utilised due to red tape, e.g. Lubavitch. No longer opportunistic appointments	Now HVs no longer immunising, strengthen Charedi nurse role	
NHSE need to review what was working e.g. children's centres. Currently refer to GP but can't get an appointment	Engagement with faith schools	
Changing landscape of provision. Difficult for professionals to stay on top - so how do we expect the mothers to know?	Should childrens' centres deliver workshops or include immunisations as part of their inductions?	
Review primary care provision sustainability		
Need to 'pool' resources and work together now rather than waiting for the next outbreak		
Improve data/record keeping.		
Need to work across roles to make every contact count		
Review resources and efficiency. 'Red tape' a barrier to immunisation		
Modify resource allocation estimates for GPs with greater than average numbers of children (community GPs have approx. 4x number of children than average)		

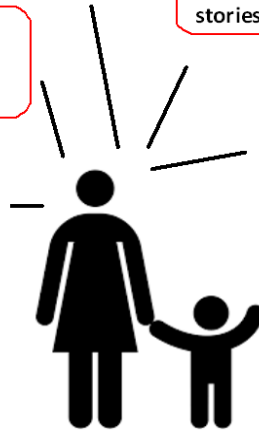
The behavioural pattern analysis and feedback meeting output enabled four broad categories of parent to be identified figure 2-5. The different categories may need differing strategies whilst also bearing in mind that there will be overlap between the 'types'

## The concerned mother – barriers and drivers

Fear vaccines may put her children at risk.

Does not consider vaccine-preventable diseases to be particularly serious – perhaps based on own experience, recent outbreaks in the community.

May trust other community members, rabbis and health workers that show respect for their community and standpoints.



Part of a smaller and very tight community with a strong internal network and little access to external mass media and internet – breeding ground for persistent rumours, stories and misconceptions.

Some common misconceptions and concerns are:

- Fear of vaccine side-effects
- Belief that very small children should not be immunized, safer to delay
- Belief that natural illnesses are better for the child
- Concerns about multiple injections (pain)
- Concerns about multiple antigens (side-effects)
- Concerns about possible scars (BCG)
- Understanding that vaccines do not work well – so no point in immunizing

### Actions may include

- Work with the community to help bust myths, e.g. engaging rabbis, mother-to-mother initiative, articles on immunization in Charedi media.
- Job aid for health workers as a help to answer difficult questions.

## The community-focused mother – barriers and drivers

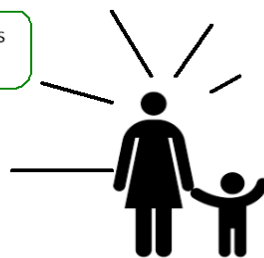
Wishes to comply with social norms in her community.

Does not consider immunization to be an important social norm in the community

Concerned about how the community is perceived by others.

Authoritarian – with the rabbi as the most important authority, but also with doctors and nurses as authorities whose advice is valued.

Finds it important to keep her children and the children of the community safe and protected.



### Actions may include

- Strategically utilizing religious/community messages, communication channels and advocates to **make immunization a social norm in the community**, e.g. old testament quotes on protecting children; statements from rabbis; pamphlets produced by community stakeholders e.g. incl. input from different rabbis; vaccination included in the annual Passover book; engaging rabbis and other prominent figures in advocacy; communicating through community media. Messaging may also include focus on protecting the community from harm and on how outbreaks may damage the reputation of the community (the latter to be used with care and *only* by insiders).
- Strengthening the role of health workers as authorities whose advice is valued, e.g. including religious references in job aid for health workers; cultural sensitivity training for health workers.



## The busy mother – barriers and drivers

Running a large household with responsibility for children, kosher food, Jewish holidays and much more.

Feels that clinics are busy with long waiting time and not child-friendly.

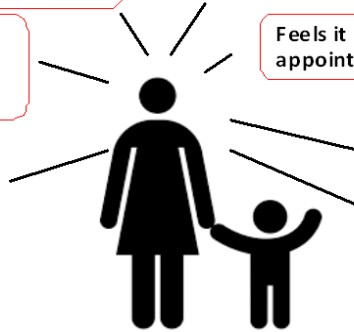
Competing priorities. No time or energy to read or respond to letters from the GP.

Feels it is complicated to make appointments. If appointment missed – no rebooking made.

Not sure about the child's vaccination status.

Unaware of the flexible solutions that are available (walk in clinics and similar).

Loves and is proud of her big family and wants to protect her children and keep them safe.



### Actions may include

- Easy access, flexible services, walk in services, easy to book opportunities.
- Making sure these mothers are fully aware of more flexible opportunities
- Reminder aids, e.g. wall calendar, refrigerator magnets (keeping it simple, no time to read long brochures)

## The mother who is sceptical of health authorities – barriers and drivers

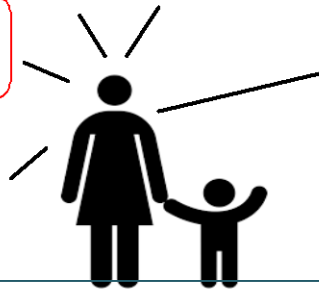
Does not feel respected by health workers.

Does not trust NHS, PHE and the messages they convey – e.g. feels they are overstating threats.

May have had a bad experience at a health facility, or knows someone who had.

The fact that GPs are paid for immunising affects their trust in them.

May trust other community members, rabbis and health workers that show respect for their community and standpoints.



### Actions may include

- Efforts by all stakeholders to create positive moments for mothers and children at health facilities. Including through cultural sensitivity training for all staff at health facilities (including receptionists and others), job aids for health workers with focus on how to appeal to this particular community, flexibility, positive atmosphere (even if she missed the last appointment or is late...).
- Engaging community stakeholders in communication about immunization, perhaps leaving out national authorities.
- Ensuring moderate messaging, as overstated messages are not considered credible

## Part 6 Outlining the Recommendations

# Discussion

Data analysis confirmed that recurring outbreaks of vaccine preventable disease occur in the Charedi community in North East London. This combined with sub-optimal coverage of routine childhood immunisations means that the population continues to be at risk of further outbreaks with the subsequent societal and healthcare impact. Increased international travel increases the risk of disease importation to the London community, and vice versa, to other Charedi communities throughout the globe. As such, in addition to increased collaborative working in North East London, joined up working across public health departments in key countries (e.g. Israel, Belgium, United States of America and the United Kingdom) would be beneficial.

### Community engagement

Community and religious leaders have been very supportive and engaged in the TIP process, participating in stakeholder and feedback meetings, commenting on the parental survey questionnaire and participating in key informant interviews. It is important that this momentum is encouraged and sustained enabling healthcare workers and the community to work together collaboratively to protect their children from the consequences of preventable illness. Although the TIP approach did not find any evidence of religious objection to vaccination, religious leader support was highlighted as crucial to promoting immunisation. This endorsement along with regularly using community communication channels to provide accurate information and publicise immunisation sessions could be a very positive step in increasing the profile of immunisation.

### Immunisation motivators

The most commonly cited reasons for parents choosing to immunise their children, were to protect their child from illness, and also to prevent the spread of disease. This highlights motivation to protect their child and to contribute to the protection of the community. As this is a close knit community information emphasising the benefits of herd immunity as well as individual protection in information campaigns could be a powerful motivator.

### Immunisation delay

Some parents in the community choose to delay their children's immunisations. This decision appears to be a number of reasons including a perceived negative vaccine experience or a mistaken belief that waiting until a child is older minimises any risk. Rather than protecting the child, this delay leaves infants to be vulnerable to vaccine-preventable diseases, at a time in their life when they are most susceptible to poor outcomes. Targeted and sustained information and support are therefore needed to strengthen vaccine

confidence of these parents, or at the least to ensure that such children are indeed “caught” up when the parent is comfortable.

## Communication

Most of the Charedi community don't access traditional media and as such immunisation information campaigns may not reach the community and myths may take longer to debunk. Satisfaction with immunisation information is considerably lower than in the general population and interventions to address this should consider using community specific communication channels. Social norms have an important role to play in immunisation behaviour and although immunisation uptake in the community is sub-optimal most parents do have their children fully immunised. This message should be used reinforce positive behaviour, perhaps in conjunction with community champions.

## Immunisation services

GP practices in the north of Hackney have a disproportionate number of young children, placing extra pressure on primary care services. Parents with large families have additional requirements when attending for immunisation appointments and competing priorities within families means that immunisation may not always be top of the agenda. This means that services must be accessible and appropriate to the needs of the community. General practice has a huge role in the provision of immunisation services and extra support may be required to ensure that the services are appropriate to the needs of the community. The most cited option by parents for improving immunisation coverage was that of reducing waiting times for immunisation appointments, and more child friendly facilities. Sunday appointments text message reminders and home visits were also popular with some parents. All of these options have cost implications but these need to be compared with the healthcare and societal costs of outbreak management, disease treatment including hospital admission and supplementary immunisation activity. Any new interventions should be fully monitored and evaluated to ensure effective, cost effective sustainable solutions can be commissioned.

This work, has benefited from a collaborative approach from stakeholders including PHE, community members, the local authority, NHS England and the local NHS acute trust. Going forward, such collaboration will be required for recommendations to be considered and implemented. This report is written at a time of on-going change in national and local public health commissioning and provision, which must be acknowledged.

## Recommendations

In light of the current organisational changes within the NHS and Local Authorities, it is important that commissioners and providers recognise the unique vulnerability of the community to vaccine-preventable diseases, and the impact this has at local, national and international levels to meet agreed targets such as measles elimination. The risks of a loss of historical memory with current changes should be monitored and efforts to mitigate this undertaken. The following recommendations are made to further tailor and protect commissioning and provision of children's immunisation and health protection services for the community:

## Commissioners:

- Undertake a review the provision of Primary Care Services in the community due to the high number of children, reports of long waiting times for appointments and other access issues for parents/carers with young children. The review should include all aspects of the immunisation service to ensure the requirements of the community are being met. If required, a full Health Needs Assessment should be undertaken.
- Consider sustainable, flexible commissioning of community based immunisation, in children's and family centres and investigate the potential for initiatives such as Sunday or home-based appointments. Also consider the use of community champions or increasing the provision of Charedi immunisation nurse specialists. Ensure any new immunisation initiatives are fully evaluated. This should include ensuring providers' have efficient systems in place to identify community members and record immunisations given, feeding back to General Practice where appropriate
- Develop a communication strategy to; improve awareness of the risks of not vaccinating or delaying vaccinating children, and ensure that parent/carers are aware of the immunisation status of their children. The communication strategy should be developed in collaboration with key local stakeholders; LA, PHE and representatives from the Charedi community and be woven into the borough immunisation improvement action plan.
- Explore ways to improve data capture of community membership to both improve knowledge of immunisation coverage (for monitoring and evaluating interventions), and to aid earlier detection of outbreaks within the community.

## Providers:

- Consider providing cultural awareness training for relevant staff
- Consider the employment of Charedi community members in relevant immunisation posts
- Explore ways to make the booking of immunisation appointments more accessible for parents
- Ensure immunisation provision meets the needs of the community. Maintain and increase access to children's immunisations, including considering community based clinics, Sunday appointments and the utilisation of staff from the community where appropriate.
- Plan immunisation clinics so that there are child friendly facilities e.g. protected space to park buggies, play areas for older siblings and keep waiting time to a minimum.
- Work with the community to develop interventions to improve parent/carer knowledge of the immunisation status of their child(ren).
- Develop communication strategies to improve parent satisfaction with immunisation information and target commonly held immunisation myths.

- Work with commissioners, community members and HPT to ensure accurate, community sensitive communications. Explore the potential to use community newsletters, to share immunisation information and advertise community clinics.
- Ensure parents/carers who delay or refuse for their child(ren) to be immunised, or those for whom immunisations are contraindicated on health grounds, understand the risk and are encouraged to keep them away from others thought to be infectious (e.g. in the case of a school outbreak).
- Develop a system to re-contact those choosing to delay childhood immunisations to ensure eventual catch-up.
- Ensure all GP surgeries have an effective systemic call and recall system, to ensure eligible children are encouraged to attend for their immunisation appointments.
- GP surgeries to consider adopting text message appointment reminders for immunisation appointments,
- Providers should ensure that there are systems in place to accurately record immunisation history and to inform the child's GP when the immunisation takes place outside General Practice. Providers should also consider recording community membership to ensure uptake can be accurately assessed and services planned accordingly.
- Consider repeating a parental satisfaction survey on a 2 yearly basis to track issues over time
- Explore ways to improve recording of community membership to improve immunisation coverage data and to enable monitoring and evaluating of community specific interventions.

### Health Protection Services:

- Increased communication between public health departments serving Charedi communities across the world, to share information on disease trends, tailored health resources and evaluations of tailored interventions.
- Explore ways to improve data capture of community membership to aid earlier detection of outbreaks within the community.
- Work closely with commissioners, providers and the community to share evidence based immunisation and VPD information

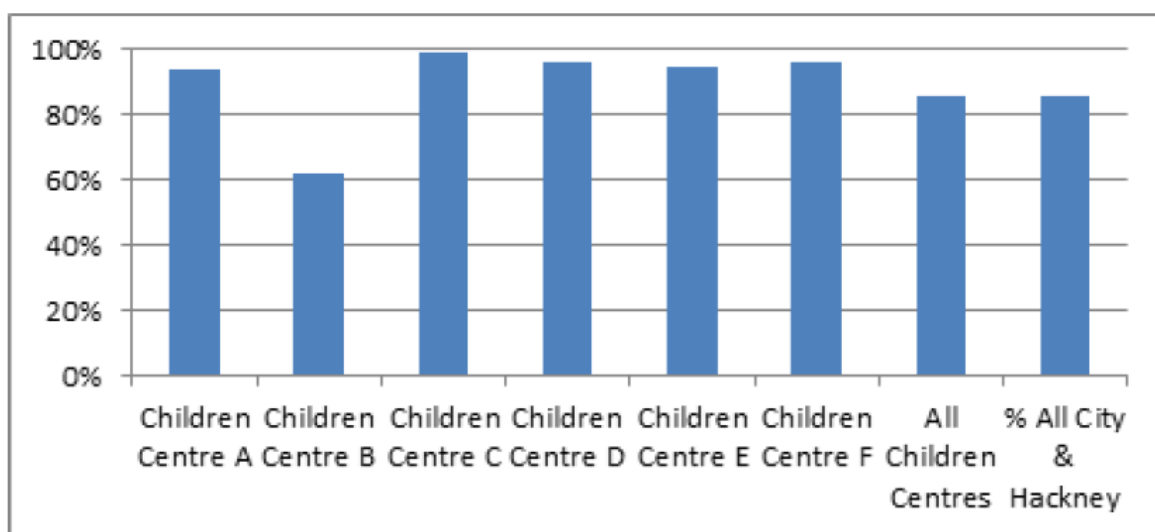
### Community:

- Continue to provide cultural training programmes for commissioners, providers and health protection staff.
- Consider including relevant immunisation information and publication of clinic details in community newsletters
- Continue to work with healthcare team to ensure that the information provided is culturally sensitive
- Explore the nomination of community champions for immunisations.
- Consider how religious leaders could further promote and support immunisation within the community

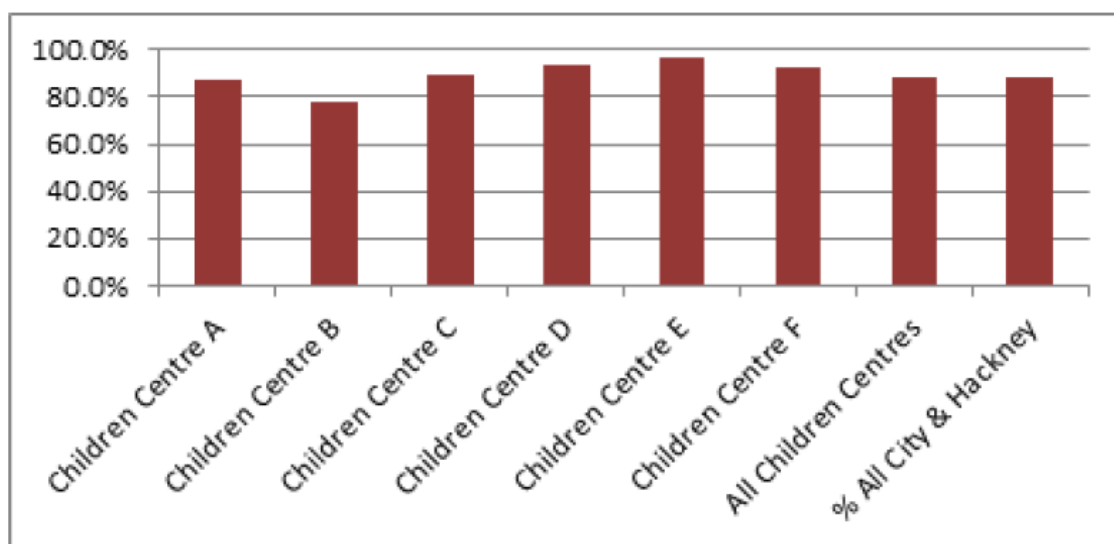
### Appendix 1

## Immunisation uptake and General Practice Provision in the Charedi community

The Homerton University Hospital NHS Foundation Trust mapped immunisation uptake data of children (with a City and Hackney GP) according to the geographical location of their practice. GP practices are grouped to show their children centre association, of which there are six spaced across the London borough. The coverage of children’s immunisations has increased across the London borough of Hackney over recent years. However, coverage within the north of the borough is markedly lower than that of the rest of Hackney, graph 1 shows coverage of the 5 in 1 vaccine by 1 year of age by children centre areas (the Charedi community are predominately resident within Children Centre area B), 1.Uptake at 12 months in all areas except area B is above 90%, whereas in area B it is only 61.9%). The difference for MMR by 2 years is less marked but still lower than all other Children Centre areas (Graph 2).

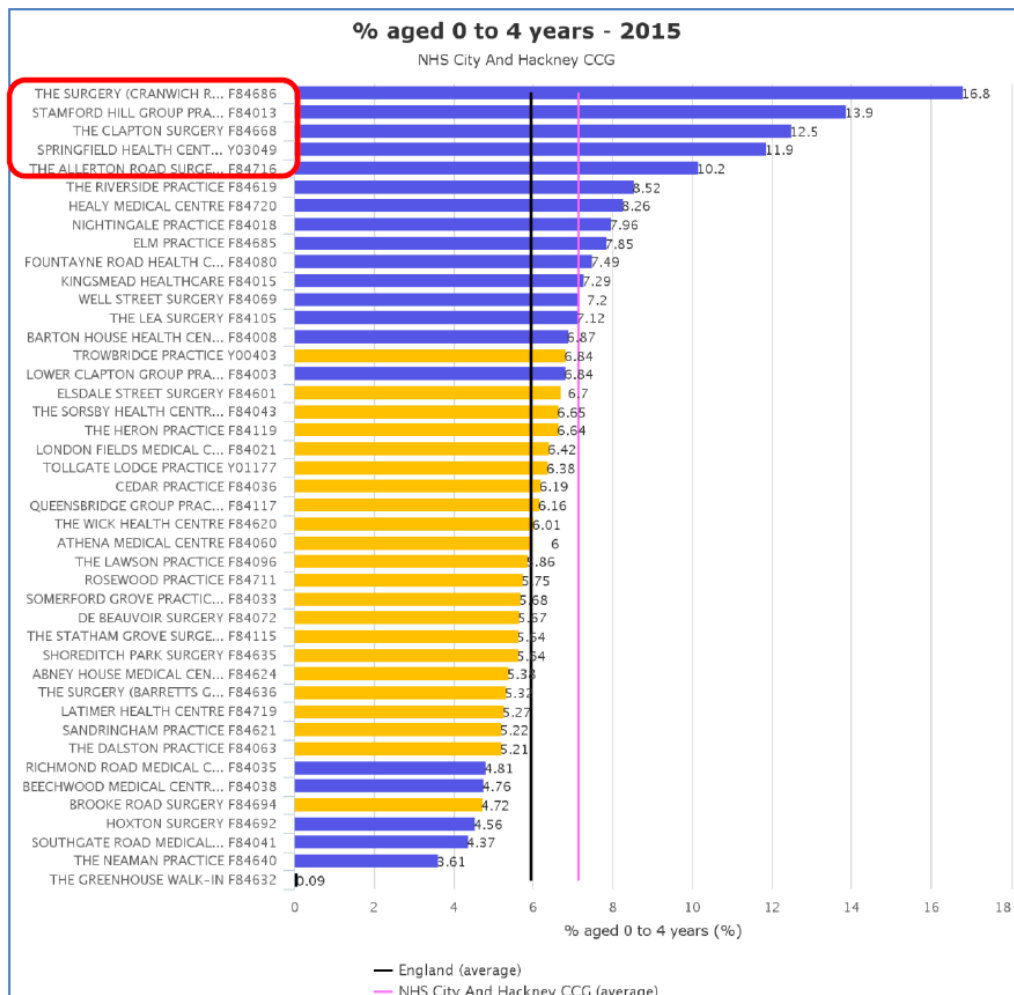


**Graph 1:** Coverage of the 5-in-1 vaccinations, by 1 year, in the London borough of Hackney, according to Children Centre area (quarter 4, 2014-2015)



**Graph 2:** Coverage of the MMR vaccination by 2 years of age, in the London borough of Hackney, according to Children Centre area (quarter 4, 2014-2015)

PHE practice profile data1 illustrates the disproportionate number of children (0-4 years) registered at the key GP surgeries (highlighted in red) serving the Charedi community (figure X), which is around double the average in England (12%). The practices with blue bars have a significantly different proportion of 0-4 year olds compared to the England average, and the yellow bars indicate no significant difference. The chart suggests that paediatric services in these GP surgeries will be in high demand.



Graph: Proportion of registered patients aged 0-4 years in GP surgeries in City and Hackney Clinical Commissioning Group

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## Appendix 2

### Literature review

Research, reports and expert opinion for reasons as to why vaccination coverage is sub-optimal within this community globally offer multiple influencing factors. Limited UK-based data is available to understand the reason for low coverage in this community, but research internationally suggests that uptake is influenced by factors, which include:

#### Birth order:

A study of over 100,000 Israeli children (including Jewish, ultra-orthodox Jewish and the Arab population) identified that a child's birth order was inversely related to vaccination status (of a voluntary varicella vaccine)<sup>i</sup>. This factor was identified to be of more significance than family size, country of birth and social and demographic parental features. A 2008 case-control study of a measles outbreak in a town close to Jerusalem found child's rising birth order to be inversely associated with their registration at a well-baby clinic (where infant immunisations are provided)<sup>ii</sup>. Of all measles cases, 82% of firstborn children were registered, compared to 44% for those fifth-born or above, compared to 100% and 96% respectively in controls. Birth order was also identified as a risk factor for "vaccine underutilization" in a study of 430 ultra-orthodox Jewish children in Israel conducted in 2011<sup>iii</sup>.

Factors such as birth order are not unique for this community, but have been reported as being of importance in other countries and communities, each suggesting a relationship between parental ability to dedicate and prioritise the time needed to arrange and attend for childhood immunisations. Additionally, it is suggested that experience perhaps of a VPD in a younger child may reduce the priority a parent gives to immunisation for other children.<sup>ivvvi</sup>

#### Health beliefs:

Studies have demonstrated differing opinions as to the importance of this factor within the communities. A 2008 UK based study concluded that participants linked low uptake to concerns over safety and danger relating to immunisations<sup>vii</sup>. These findings differ from those of other studies in communities in the UK and overseas. Very little other UK-based research has been published about the London community, with the next previously available and related article dating back to 1994. This paper illustrated results from a questionnaire study in north-east London, of 67 orthodox Jewish parents identified that they considered immunisation to be important and had positive attitudes to the value and safety of immunisations<sup>16</sup>. It is important to note that this study was conducted before the global MMR scare in 1998. The 2008 study did not find uptake was affected by practical difficulties or perceived insensitive cultural practices of health providers. The 2011 Israeli study used medical records and parental interviews to identify factors for sub-optimal immunisation coverage in children. In addition to birth order (having >6 siblings), maternal education, parental religious beliefs against vaccination, perceived risk of VPDs being low and a mistrust of the Ministry of Health were also identified<sup>12</sup>. The authors concluded that increased health education and involvement of religious leaders would likely both significantly aid an increase in immunisation coverage.

## Access to immunisations:

Access to health or specific immunisation services is consistently highlighted in the literature<sup>viii</sup>. Access is affected by the number of children within the family unit (reducing parental time) and services within schools. For example, a Belgium study noted that during a measles outbreak in 2011-12, an important factor for non-vaccination of children within orthodox Jewish communities was their attendance of private schools, which were not supported by a school health centre<sup>ix</sup>. Additionally, in Belgium, these schools did not receive a MMR catch-up programme<sup>x</sup>.

## Vaccine preventable diseases

Despite efforts, multiple outbreaks of vaccine-preventable diseases (e.g. measles and mumps) within Orthodox and Ultra-Orthodox Jewish communities across the world (Europe and the United States of America) have been, and continue to be reported<sup>xi-xvii</sup>. A report of a measles outbreak in

2004 in Jerusalem resulted in 117 cases, including eight hospitalisations and one death in a child with an underlying lung disease<sup>xviii</sup>. The number of outbreaks, recurrence and their size indicate inadequate vaccination coverage, and their confinement, illustrates a significant degree of social segregation. International travel increases the risk of disease importation to the London community, and vice versa, to other Charedi communities throughout the globe<sup>xix</sup>. Disease outbreaks cause a considerable burden of ill health to those whom acquire infections. A study in England of 203 persons who had been confirmed to have measles identified that persons had a mean time off work or school of 9.6 days, a mean duration of perceived illness of 13.8 days, highlighting the impact of this infection<sup>xx</sup>.

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<sup>ii</sup> Stein-Zamir C *et al*. *Who are the children at risk? Lessons learned from measles outbreaks*. *Epidemiology of Infection* (2012), 140: 1578-1588.

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## Appendix 3 - Measles in Hackney and the Charedi community, 2006 – 2013 January 2016

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## Background

Measles is a vaccine preventable disease caused by a virus. It is highly communicable and presents with prodromal fever, conjunctivitis, coryza and koplik spots. This is followed by a rash that begins on the face and spreads to all the body. (1)

There are a number of complications associated with measles infection. The most common ones are otitis media (7 to 9% of cases), pneumonia (1 to 6%), diarrhoea (8%) and convulsions (one in 200). (2) More rare complications include encephalitis and sub-acute sclerosing pan-encephalitis. The case–fatality ratio for measles is high in children under one year of age and rises again in teenagers and adults with malnourished or immunosuppressed children being at higher risk. (2)

In the UK children are routinely offered two doses of MMR. The 1<sup>st</sup> dose is offered at 12-13 months of age and the second is offered at the age of three years and four months.

In 1998 a paper reporting a small number of case series by Wakefield et al was published. This and the subsequent media storm suggesting a link between MMR vaccination and the development of autism and bowel disease in infants led to a significant number of parents losing confidence in the vaccine and uptake dropped across the UK. Although confidence in the vaccine has recovered with uptake levels in the infant programme surpassing pre-Wakefield levels there have been a number of measles outbreaks, mainly due to pockets of under-vaccinated children from that time. There are some communities in the UK with sub-optimal immunisation coverage. This includes the Charedi (ultra-orthodox Jewish) community, within which immunisation levels are consistently below the WHO recommendation of >95% of children vaccinated in each new birth cohort for herd immunity to be achieved. (3)

The largest Charedi community in Europe is based in the London borough of Hackney. In quarter 4 of 2014/15, UK coverage of the 1st dose of MMR at two years was 92.5%. In City and Hackney it was 87.9% and for the area where the Charedi community is mainly based uptake was 78.3%. This leaves the community vulnerable to continuing outbreaks. For example, in 2013 a total of 1,843 laboratory confirmed cases of measles were reported in England and Wales with 26% (474) of these cases being diagnosed in children less than 4 years of age. A total of 192 (10.4%) were residents in London. (4) Of these, 73 (38%) were residents in Hackney.

Anecdotal reports suggest that suboptimal immunisation levels in the Charedi community in Hackney are likely to be due to the following factors: the predominance of large families with large numbers of young children, difficulties in health service access and health beliefs. This results in an important number of children not being immunised making this community more susceptible to disease and outbreaks.

Public Health England (PHE) and NHS England (London) are working together with WHO Regional Office for Europe to increase vaccination coverage in the Charedi community. With the emphasis put on measles and rubella elimination by 2015, WHO Europe has developed a “Guide to Tailoring Immunisation Programmes”. (5) The guide provides methods and tools to enable teams working with under vaccinated communities to design targeted strategies with the aim of increasing uptake of infant and childhood vaccinations. (5)

As part of this project the objective of this report is to quantify the burden on the Charedi community by describing the cases of measles reported between 2006 and 2013 in residents in Hackney by Lower Layer Super Output Area (LSOA) and year and identifying whether the individuals involved were members of the Charedi community or not.

## Methods

### Data sources

HPZone is a web-based support tool designed to be used by staff at the local Health Protection Teams. HPZone provides workflow mechanisms to support all the key business processes of a Health Protection Team, from the handling of routine enquiries, through Case management and Contact tracing, right up to the management of Outbreaks and Incidents. We used this data source for the period between 2010 to 2013.

We also obtained data from a Local Access database used prior to HPZone where details of all the cases of measles were held. We used this data source for the period between 2006 to 2009.

### Data collection procedure

All the cases were allocated an LSAO based on the Office of National Statistics 2001 and 2011 census using ArcGIS version 10. (6)

Operational definitions

#### 1. Confirmed case of measles:

- Measles IgM positive in blood or oral fluid in the absence of a history of recent vaccination:
- Confirmed wild measles RNA positive on any clinical specimen

## 2. Probable case of measles which includes:

### Suspected case of measles:

- Any person in whom a clinician suspects measles infection, or
- Any person with fever and maculopapular rash (i.e. non-vesicular) and one of the following: cough or coryza (runny nose) or conjunctivitis (red eyes).

### Epidemiologically linked case of measles:

- A person with signs and symptoms consistent with measles who was in contact with a laboratory confirmed case 7-18 days before the onset of symptoms

### Data analysis

Possible cases were discarded and confirmed and probable/suspected cases were merged together for the purpose of constructing maps. Overall rates per year were calculated using an estimate of the proportion of the Hackney population that is likely to belong to the Charedi community as shown in the report “Counting Hackney’s population”. (7) We used the proportions described in this study to estimate the numerator (proportion of the total cases of measles likely to be part of the Charedi community) and to estimate the denominator (proportion of the Hackney population per LSOA that are likely to belong to the Charedi community).

The data was aggregated by year and LSOA and rates per thousand population were calculated for each LSOA using R version 3.1.2. The rates per LSOA were then plotted in a map using ArcGIS version 10. Whether a case belongs to the Charedi population is not routinely recorded in the case’s notes. For that reason measles rates and proportion of Hackney population that are likely to be from the Charedi community were mapped by LSOA in order to match the distribution of rates per thousand population with the distribution of the Charedi community.

The proportion of the population of Hackney likely to belong to the Charedi population was also presented in map form by LSOA using the same software. The data for this purpose was kindly shared by the team that produced the report “Counting Hackney’s population”. (7) This data was only available for the LSOAs under the 2001 census. For the new LSOAs under the 2011 census we allocated the same proportion of population belonging to the Charedi community as the LSOA under the previous census.

### Results

For the period 2006 to 2013 a total of 664 cases of measles (probable and confirmed) in Hackney were reported to the NECL-HPT. This represents a rate of 36 cases per 100,000 population for the entire period in Hackney. The rates per year are presented in Table 1.



*Table 1: Cases of measles (probable and confirmed) and estimated crude measles rates per 1000 population by year and by whether the population they are likely to belong to, Hackney 2006-2013*

Year	Total number of cases	Rate per 100,000 population		
		Overall	Charedi	Non Charedi
2006	63	30.08	8	28
2007*	276	131.14	503	90
2008	42	19.73	28	18
2009	35	16.20	4	16
2010	8	3.65	4	3
2011	59	23.87	76	21
2012	78	30.94	35	34
2013*	103	40.02	280	27

\*Outbreak years

The rate of measles for the Charedi community between 2006 to 2013 was 117.34 per 100,000 population compared to a rate of 29 per 100,000 for the rest of the Hackney population (Table 2). During the outbreak years (2007 and 2013) the estimated rates of measles for the Charedi community were five to ten fold higher than the rates observed in the (probable and confirmed) by age category and year of reporting, Hackney 2006 to 2014 rest of the population in Hackney. Apart from the years 2006 and 2009, the estimated rates of measles in the Charedi community remained higher than in the non Charedi population.

Table 2: Overall cases of measles and estimated crude measles rates per 100,000 population by Charedi and non Charedi population, Hackney 2006 to 2013

	Rate per 100,000 population	
	Charedi population	Non Charedi population
<b>Total number of cases (2006-2013)</b>	156	496
<b>Population</b>	132849	1691759
<b>Overall Rate per 100,000</b>	117	29

For the study period 2006-2013, 53% (350) of the cases were male and 45% (299) were under 4 years of age, with a median age of five years of age (range under 1 year of age to 63). The age and sex distribution of cases has remained constant through the different years (Graph 1).

Graph 1: Cases of measles



# Measles outbreak in North East London and the Charedi Community, 2012/2013

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*Exploration of reasons for low uptake of the MMR vaccination in the community using secondary data*

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## Executive Summary

The Charedi community in North East London have low up take of the MMR vaccination, evidenced by low rates of vaccinations for GP practices known to cover areas where this community largely resides and the measles outbreaks that occur from time to time in the same areas. One such outbreak occurred in late 2012 and continued for nine months, with around 150 cases belonging to the Charedi community. The cases ranged from 2 months to 49 years old. The outbreak was largely driven by unvaccinated or partly vaccinated cases who were old enough to be vaccinated with two doses of MMR vaccine but were not. 17% of cases were too young for vaccination.

The outbreak was managed by the North East and North Central London Health Protection Team. HP Zone was used for record management during the outbreak. In this paper, the information recorded during the outbreak is explored to find reasons for lack of vaccination in cases and other children in their families with the aim of providing insight that can be used to understand the population and prioritise action using the WHO Tailoring Immunisations Programme approach.

Records were reviewed for 143 cases and 162 siblings living in 94 families. Conversations with caregivers (mainly parents) were studied to find reasons expressed for lack of vaccination. A third of the families expressed negative feelings about MMR vaccinations expressing range of reasons including fear of adverse effects, waiting until the child was older, preferring natural infection and not believing the evidence for vaccination. Most families did not express negative feeling about vaccinations and suggested that lack of vaccination is due to confusion about whether the child was immunised and a lack of time to take children to be vaccinated. There was no suggestion of religious reasons for lack of vaccination. The siblings of the cases also had low rates of MMR vaccination.

Birth order and large families have previously been shown to be inversely associated with fully vaccinated status. Analysis using data collected for this outbreak also suggested that younger children are less likely to be vaccinated. It was not possible to draw any conclusions about the influence of family size, although some families reported that a lack of time for vaccinations due to large families. There was little suggestion of access to healthcare being a major factor in low uptake of immunisations, although some families seemed to be registered with private GPs which may mean that messages about the importance of timely vaccinations is not getting to the families.

There are a number of reasons for caution in interpreting the findings – mainly due to biases and errors in the way the data might have been collected and because of missing data. However, the findings suggest that addressing vaccination fears and myths and checking vaccination status of children at the time of any clinical contact with parents may increase rates of vaccinations.

## 1. Background

In 2012/2013, the North East and North Central London Health Protection Team (NENCL HPT) managed an outbreak of measles in the Charedi (Ultra-Orthodox Jewish) community based in North East London (Hackney, Haringey and Barnet) (1). 154 cases of measles were notified to the HPT between 20/12/2012 and 26/08/2013.

The spread of measles in this community was facilitated by a large pool of unimmunised or partially immunised individuals and a high contact rate due to large families with many children and social mixing in educational establishments and national and international camps (1). Transmission was observed within households, extended family groups, nurseries, schools, and a camp for Orthodox Jewish teenagers attended by 80 girls (mainly from Hackney) with staff from Italy.

The Charedi community in North East London is known to have sub-optimal rates of vaccination (2,3,4) and outbreaks have occurred before in the same community (5,6). Measles outbreaks have been also reported in Orthodox Jewish communities in other parts of the world (7,8). Outbreaks are often facilitated by the high movement of the members of the community between countries (9,7). A measles outbreak in New York (United States of America) in 2013 started with the arrival of an intentionally unvaccinated 17 year-old case from London in March 2013 (10).

There have been previous studies of immunisation uptake in this community. Two studies, both published prior to the MMR scare drew contrasting conclusions on the level of immunisation in the community. Cuninghame, Charlton, & Jenkins (1994) studied vaccine uptake in the Orthodox Jewish community in North East London and their attitudes towards vaccination (11). They reported a similar level of uptake in the community to that of the area using COVER data<sup>1</sup>. Some of the parents surveyed (16/67) chose not to vaccinate and most of them gave parental choice as the reason to delay vaccination. Most parents considered measles to be a serious illness. 34% cited difficulty in accessing healthcare with inconvenient clinic hours being the most common complaint. The authors concluded that the community had similar uptake to others in the area and most had positive attitudes towards vaccinations but wanted better access to healthcare (11). Another study in City and Hackney around the same time (3) also conducted (before the MMR vaccine scare) found that the Charedi community in Hackney had lower uptake compared to the rest of the population on all immunisations (strong evidence at  $p=0.05$ ). Mothers ( $n=10$ ) interviewed about reasons for not vaccinating their children cited fear of vaccine, large families, lack of time and unsympathetic treatment by practice staff. A later small qualitative study of beliefs and attitudes about vaccination in the same community found social structures to be highly influential in decisions about vaccination and despite lack of access to popular media, rumours about vaccine safety were spread by word of mouth (2).

The NENCL Health Protection Team is seeking to tackle low vaccination rates in this community by using the methods from the Tailoring Immunisations Programme designed by the World Health Organisation (WHO). This paper seeks to contribute to this work by exploring reasons for low uptake of immunisation in the families of cases reported to the Health Protection Team during the 2012/13 outbreak.

### 1.1 Tailoring Immunisations Programme

The Tailoring Immunisations Programme (TIP) is an initiative by the World Health Organisation's (WHO) Regional Office for Europe aimed at renewing focus on childhood vaccination and increase coverage (12). It has two phases:

1. The formative phase is when populations are segmented by the vaccination status of their children. This is followed by analysis of the vaccination behaviour of the caregivers (parents), providers and influencers. Target groups are then prioritised and profiled.
2. The planning phase is about using the intelligence from the formative phase to set objectives, design evidence based interventions and monitoring their impact.

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<sup>1</sup> The Cover of vaccination evaluated rapidly (COVER) programme evaluates childhood immunisation in England.

## 2. Aims of this paper

The aim of this paper is to identify reasons for low uptake of measles vaccination amongst the families of cases reported during the 2012/13 outbreak using data captured during conversations with the cases and their families as part of case management by the Health Protection Team.

Insights will be used to make recommendations for inclusion into the business case for optimising vaccination services to this community, based on the Tailoring Immunisations Programme. This paper contributes to the formative phase of the Tailoring Immunisation Programme where the population is segmented and vaccination behaviours of the caregivers, providers and influencers analysed. This paper focuses on the vaccination behaviour of the caregiver (parents) and particularly on the demand side barriers to vaccination, with some analysis of the supply side barriers, identified through conversations with parents of cases.

However, the paper is limited in only being able to analyse a subset of the target population (Charedi community living in North East London) who are known to us because of their status as cases and contacts of and so, by definition, were not vaccinated or partially vaccinated and not necessarily representative of the Charedi population.

## 3. Methods

The project uses secondary data taken entirely from HP Zone. HP Zone is a case management database used by Health Protection Teams to manage reported cases of notifiable disease.

### 3.1 Data collection

A list of cases and contacts related to this outbreak was extracted from HP Zone by the Information Officer for the NENCL Health Protection Team. Records related to the outbreak were initially found in HP Zone by searching for all cases and contacts with the context *Member of Orthodox Jewish community 2012 – 2013* which had been used to link case and contact records during the outbreak.

This list was refined as per the following case definition

*Possible, probable or confirmed case of measles in members of the Orthodox Jewish community from the three London boroughs of Hackney, Haringey and Barnet (where the local Community primarily reside) reported between 20.12.2012 and 26.08.2013.*

Manual searches were used to compile a comprehensive list of household contacts of the cases that fell in this case definition.

Fig 1 describes how the cases and contacts were identified for review.

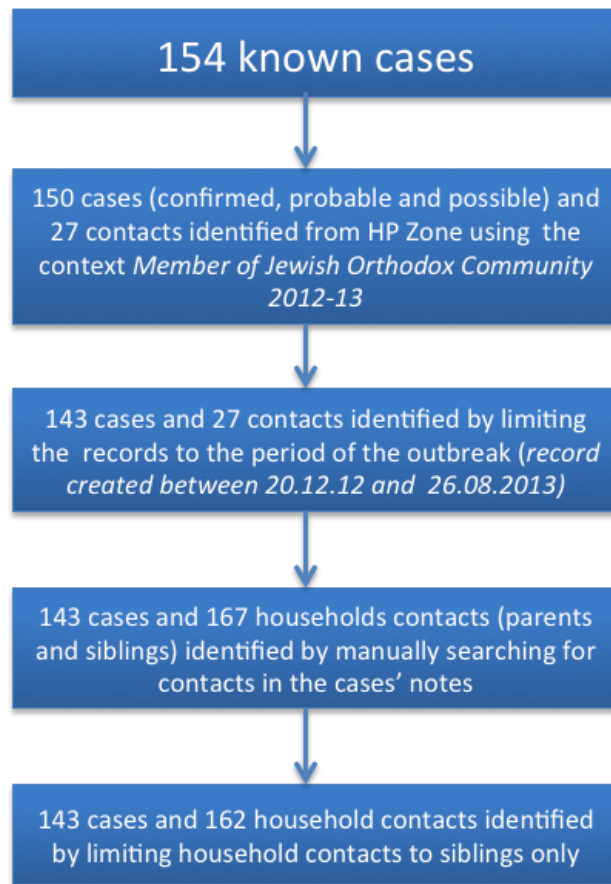


Figure 1: Data collection flowchart

It was not possible to identify all cases as not all were linked by the context. 93% of known cases were identified.

All cases were reviewed to extract relevant data. Data was only reviewed for contacts where the contacts were siblings of the case. Parents and non-household contacts were not reviewed.

The HP Zone records for cases and their household contacts were searched (through electronic and manual searches) to extract

- Demographics (name, date of birth, address)
- Date of onset and entry into HP Zone
- Vaccination status
- If not vaccinated or partially vaccinated, reasons for this. Where reasons for not vaccinating were available in the records, families were classified into the following group
  - Reluctant to vaccinate, if there was clear record of negative beliefs about vaccination
  - Possibly reluctant to vaccinate, if there was some record of negative beliefs about vaccination
  - Insufficient information in the notes, if there was a suggestion of reluctance because of vaccination status of the case and other children in the family but no record of reasons
  - Not reluctant to vaccinate, if there was clear record of discussions that suggested that the parents did not hold negative beliefs about vaccinations and were willing to vaccinate siblings in response to infection in case
- Birth order where details were available for all siblings in the family
- Any discussions on access to healthcare

Information on reasons for the cases not being vaccinated was extracted if:



- Case/contact was older than 14 months (recommended age for first MMR vaccination) and had no history of MMR vaccination
- Case was older than 40 months (recommended age for second MMR vaccination) and either had an incomplete or no history of MMR vaccination

### 3.2 Information governance

Retrieved data was stored on secure HPT servers at all times, in folders that were accessible only by those who could also access the HP Zone data (i.e. within NENCL HPT only) and were bound by patient confidentiality requirements. Where there was a need to transmit data with patient identifiable information, only PHE emails were used to do this. One of the principles of data analysis was to keep all analysis anonymous and not to identify any cases or families. Results of the analysis are to be kept within the HPT and this report is not intended currently for wider publication. For this reasons, permission was not sought from Ethics Committee to retrieve and analyse the data. This may need to be thought about if wider publication is considered given that the parents gave the information to the HPT for the purposes of clinical management.

## 4. Results

### 4.1 Descriptive epidemiology

Of the possible 154 cases, 143 records were extracted from HP Zone. Table 1 shows number of cases by confidence of diagnosis.

Table 1: Cases by confidence of diagnosis

	Confirmed	Possible	Probable	Grand Total
Number of cases	91	13	39	143

Figure 2 shows number of cases by week of onset (with 20/12/2102 taken as week 1) and confidence of diagnosis.

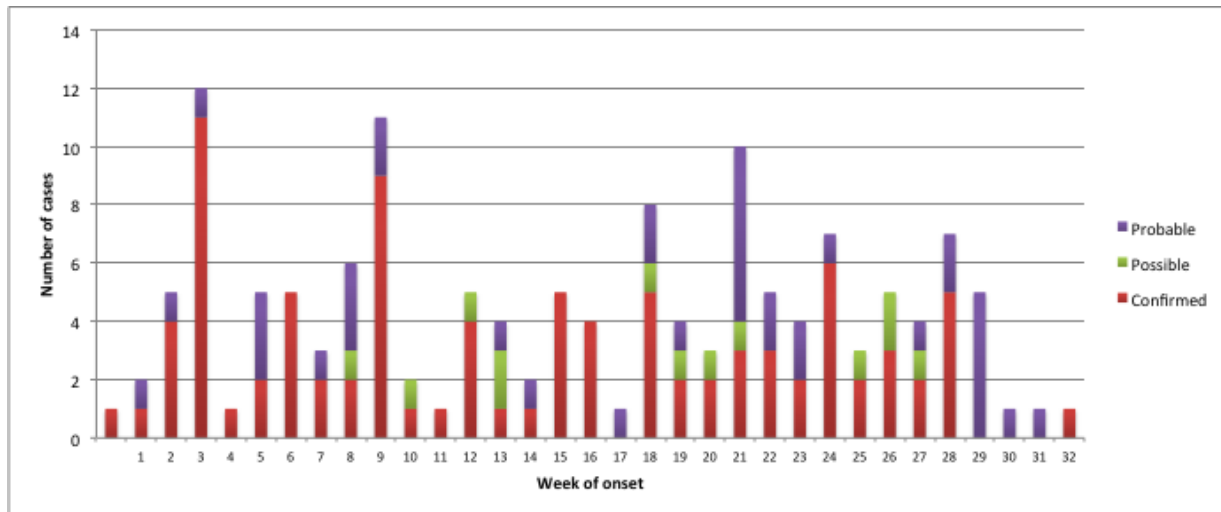


Figure 2: Epidemic Curve showing cases by week of onset and confidence of diagnosis

Figure 3 shows the number of cases by age group. The ages of the cases ranged from under 2 months to 49 year old.

- Seventeen per cent of cases (n=25) were in children under 14 months and so too young to be vaccinated with first dose of the measles vaccine. Two of these children were vaccinated with one dose.

- 25% of the cases (n= 36) were in children aged 14-40 months so too young to be fully vaccinated for measles with two doses. Unfortunately, of these only 6 children were fully vaccinated for their age i.e. had received one dose of the vaccine.
- 57% of cases (n= 82) were in children and adults who were old enough to be fully vaccinated. Of these, the majority (n= 67) were unvaccinated.

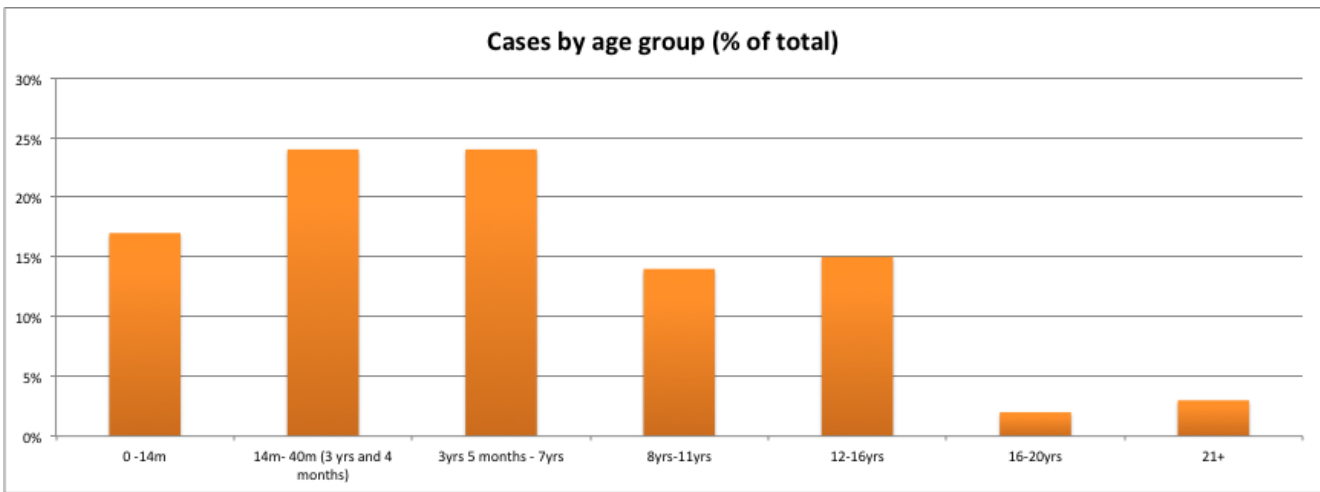


Figure 3: Cases by age group (% of total)

It was not possible to stratify contacts by age, as the date of birth was not available for a large proportion of contacts.

Table 2 shows the number of families and the number of cases in these families. Due to household transmission, 94 families accounted for the 143 cases. In families known to have two or more children, eight families had cases in all siblings. Unsurprisingly, most of these were families that chose not to vaccinate their children and so all siblings were unvaccinated or partially vaccinated.

Table 2: Number of cases and numbers of families that cases belong to

Number of cases	9	8	6	3	2	1	Total
Number of families	1	1	3	4	11	74	94

Table 3 shows the vaccination status of the 143 cases. Of these, the majority (84%) had never received even one MMR vaccine. Seventeen per cent of these were too young (less than 13 months of age) and were therefore dependent upon herd immunity for protection. Fifteen per cent had received just one MMR either because they were too young to have been offered 2 vaccines, or were incompletely immunised for age. One case reported being fully vaccinated with 2 MMR vaccines and so was classified as being a *possible* case as per the Public Health England protocol. A saliva test kit was sent to the family for confirmation of diagnosis but HP Zone has no records of a result. The efficacy of a single dose of measles-containing vaccine is around 90%. A second dose of measles-containing vaccine protects those who do not respond to the first dose [13].

Table 3: Vaccination status of cases

Vaccination Status <sup>2</sup>	Fully vaccinated	Fully vaccinated for age	Partly Vaccinated	Too young	Not vaccinated	Not known	Grand Total

<sup>2</sup>Definitions

Fully vaccinated- two MMR doses given at any age

Fully vaccinated for age- one MMR dose in children under 40 months (recommended age of 2<sup>nd</sup> dose)

Number of Cases	1	8	13	24	97	1	144
Percentage of Cases	1%	6%	9%	17%	67%	1%	

Table 4 shows the vaccination status of siblings of cases. Of the siblings who did not develop measles during the outbreak period and so were not cases, less than half (40%) were fully immunised. Of those that were partly immunised or not immunised, it is likely that a large number (especially of older age groups) had previous history of measles so were not susceptible. This was noted by some parents in discussions with the Health Protection Team.

Table 4: Vaccination status of siblings of cases

Vaccination Status <sup>3</sup>	Fully vaccinated	Fully vaccinated for age	Fully vaccinated /fully vaccinated for age	Fully vaccinated/p artly vaccinated	Partly vaccinated	Too young to be vaccinated	Not vaccinated	Not known	Total
Siblings	64	7	4	3	39	4	34	2	162
% of siblings	40%	4%	2%	2%	24%	2%	21%	1%	

## 4.2 Reasons for low vaccination uptake

The paper on the NENCL HPT project on increasing uptake in the Charedi community based on the Tailoring Immunization Programme (14) includes a literature review of the reasons for low vaccination uptake in the community. Birth order, health beliefs and access to immunisations are highlighted as the most pertinent factors from studies (although none of these studies were conducted in the UK). This evidence was taken as the basis for structuring the data extraction from HP Zone and the analysis in the paper is presented according to this structure. Much of the analysis is presented in terms of numbers of families rather than numbers of cases and/or siblings given that we can expect attitudes to vaccination to be similar for cases and contacts within families so families are an appropriate unit of analysis.

### 4.2.1 Lack of information, misinformation and beliefs

Of the 94 families who had cases of measles, 21 families (accounting for 56 cases) were reluctant to vaccinate, based on clear conversations had with them about their beliefs about vaccinations (Table 5). For nineteen families (accounting for 28 cases) there was no record of discussion of beliefs about vaccination.

---

Partly vaccinated – one MMR dose in children over 40 months

Too young- children under 14 months with no MMR vaccination history (recommended age of 1<sup>st</sup> dose)

Not vaccinated- Children over 14 months with no MMR vaccination history

Not known- no record of vaccination history

<sup>3</sup>Fully vaccinated- two MMR doses given at any age

Fully vaccinated for age- one MMR dose in children under 40 months (recommended age of 2nd dose)

Fully vaccinated/ Fully vaccinated for age - Definitions as above but records do not allow for clarification

Fully vaccinated/partly vaccinated- Vaccinated fully (two MMR doses) or partly (one MMR dose in children over 40 months where records do not allow for clarification)

Partly vaccinated – one MMR dose in children over 40 months

Too young- children under 14 months with no MMR vaccination history (recommended age of 1st dose)

Not vaccinated- Children over 14 months with no MMR vaccination history

Not known- no record of vaccination history

Table 5: Reluctance to vaccinate: all families and families with partially vaccinated or unvaccinated children only (i.e. removing families with cases who were too young to be immunised or were fully immunised for their age)

Reluctant to vaccinate?	Yes	Possibly	No information in notes	No	Total
Number of families- all	21	4	19	50	94 (143 cases)
Number of families with partially vaccinated or unvaccinated children only (i.e. excluding those with cases too young to vaccinate or fully vaccinated for age)	21	4	18	25	68 (111 cases)

Table 6 shows the vaccination status of cases by the family's reluctance to vaccinate.

Table 6: Vaccination status of cases by their families' reluctance to vaccinate

Reluctant to vaccinate?	Fully/fully for age	Not vaccinated	Partly	Not known	Too young	Total cases	Total families
Yes		52	1		3	56	21
Possibly		4	1		1	6	4
No information in notes		23	4	1		28	19
No	9	18	7		19	53	50
Grand Total	9	97	13	1	23	143	94

#### 4.2.1.1 Factors affecting uptake in families reluctant to vaccinate

For the 25 families that were definitely or possibly reluctant to vaccinate, information on reasons was not available in the majority of the cases (Table 8). Nine families were concerned about the safety of the vaccine or did not believe its effectiveness or chose "natural infection". Some records note the reluctance of the parents to change their mind despite lengthy conversations with members of the Health Protection Team about the evidence for vaccinations. At least one record notes a disagreement between the father and mother on the benefits and risks of vaccination. Appendix 1 lists the reasons given by the families.

Table 8: Reasons offered by parents for not vaccinating children

Reasons for not vaccinating	"Medical advice"	Chooses to wait until child is older	Does not believe evidence	Does not engage with health services	Fear of vaccine	Prefers natural infection	Not known	Grand Total
Number of families	1	1	1	1	7	2	13	25 families (62 cases)

#### 4.2.1.2 Factors affecting uptake in families reluctant to vaccinate

The factors affecting lack of uptake in families that do not hold negative beliefs about vaccinations (50 families, 53 cases) are almost more interesting as there is greater scope to change behaviour in this group.

A qualitative analysis was done of the reasons given by this group not vaccinating or partly vaccinating their children. This analysis was only done for families where the cases were old enough for vaccination (14 months or over) and were unvaccinated or only partly vaccinated (25 families, 25 cases).

Two main themes emerged

- Parents did not know that child was unimmunised and often self-reported immunisation status and GP recorded immunisation status were inconsistent
- Parents cited lack of time, particularly due to large families

Fishbein's Theory of Reasoned Action states that the intention to carry out certain behaviour is influenced by a person's *attitude towards the outcome* and *social norms*.

Attitude towards the outcome is dependent on beliefs that the behaviour leads to certain outcomes and the evaluation of these outcomes. There was evidence that a number of parents did not believe measles infection to be serious. This was evidenced by lack of vaccination of cases in this outbreak despite previous history of infection in siblings as well as reluctance to vaccinate unprotected siblings during this outbreak. In one case, the parents were unwilling to consider any prophylaxis advice, including human normal immunoglobulin (HNIG) for vulnerable contacts<sup>4</sup>.

#### 4.2.2 Access to healthcare

Access to health care was investigated given the evidence from literature that poor access can result in poor uptake of immunisations. In this outbreak, there was no suggestion of perceived lack of access to healthcare in the discussions. However, at least three of the ninety-four families had a private GP which might suggest a lack of engagement with the NHS and this might be detrimental to vaccine uptake if the private GPs do not have the same focus on timely vaccinations as NHS GPs, or indeed offer vaccinations at all. Whilst only three such instances and recorded, one record of discussion with the private GP suggested that there were a number of families registered with him. At least one parent did not speak English and discussion was conducted via an interpreter, as such, their own access to health services may be hampered.

#### 4.2.3 Birth order

Evidence from the Jewish population in Israel suggested that a child's birth order is inversely related to his/her vaccination status (of a varicella vaccine) and that this is a significant factor in explaining low uptake (14).

Full family details i.e. number, ages and vaccination status of siblings were extracted manually from HP Zone. 51 of the 94 families (accounting for 81 cases and 130 siblings) were included in this analysis as they had two or more children and information was available on all siblings. However, not all siblings were included in the analysis. Children too young to be vaccinated were excluded. Remaining families either only had one child or the information on number of siblings and or their vaccination status was not available.

Our data suggests a similar pattern to that reported in literature. As the birth order increases (i.e. the younger the child in the family) the general trend is towards a reduction in the percentage of children of that birth order that are fully immunised. Beyond the 6<sup>th</sup> child, the analysis becomes unreliable due to small numbers of children (see table 9). Additionally, 7 of the 18 children in the 7 and above birth order group belong to one family and all of them were immunised. Therefore the data at this extreme is difficult to interpret because of correlation between the children due to membership of the same family. Figure 4 displays this in a graph and table 9 shows the data.

Percentages are calculated across the row. For example, 42% of all children of all families that are first born have a record of being fully immunised (or fully immunised for age). Children too young for vaccination have been removed from the analysis.

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<sup>4</sup> Recommended to prevent or attenuate a measles attack in a contact that is either immunocompromised, pregnant or under the age of 9 months (PHE Immunoglobulin Handbook. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/327772/Measles\\_immunoglobulin\\_May\\_2009.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/327772/Measles_immunoglobulin_May_2009.pdf))

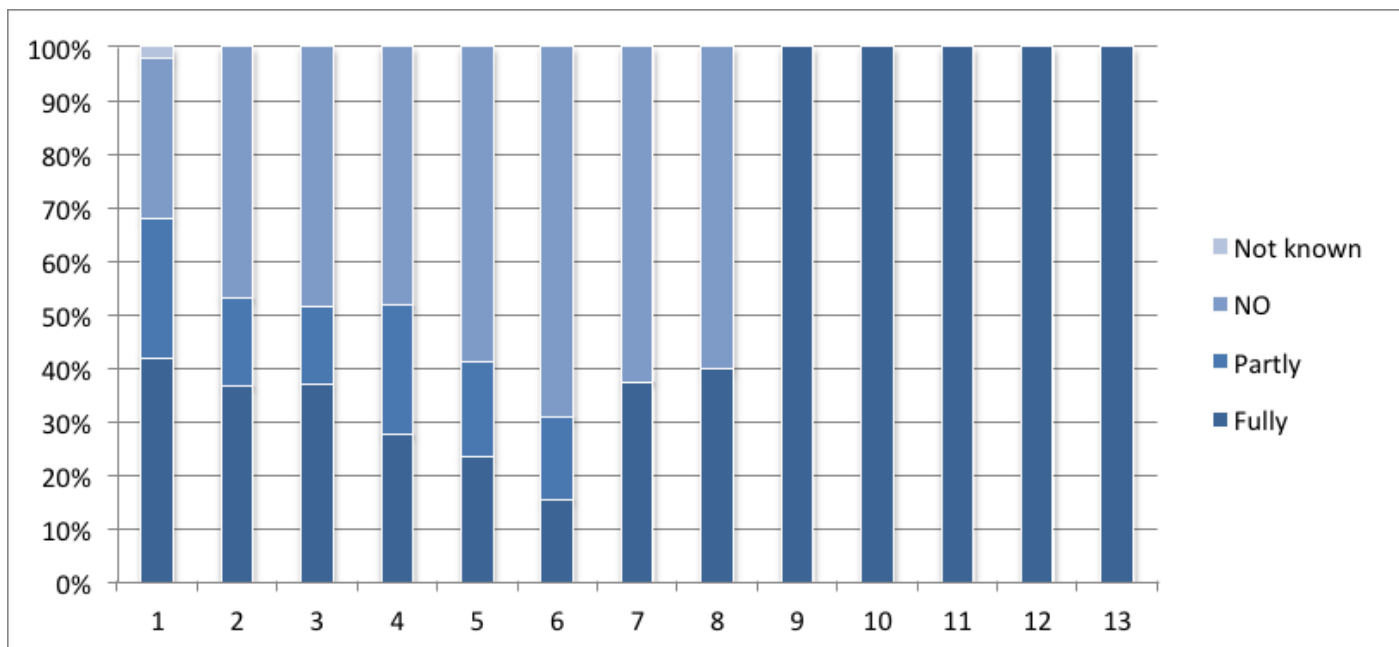


Figure 4: Vaccination status of cases and siblings by birth order (for families with more than one child)

Table 9: Vaccination status of cases and siblings by birth order (for families with more than one child)

	Fully vaccinated (including fully vaccinated for age)	Not vaccinated	Partly vaccinated	Not known	Total number of cases and siblings
1	21(42%)	15 (30%)	13 (26%)	1 (2%)	50
2	18 (37%)	23 (47%)	8 (16%)		49
3	13 (37%)	17 (49%)	5 (14%)		35
4	8 (28%)	14 (48%)	7 (24%)		29
5	4 (24%)	10 (59%)	3 (18%)		17
6	2 (15%)	9 (69%)	2 (15%)		13
7	3 (38%)	5 (63%)			8
8	2 (40%)	3 (60%)			5
9	1 (100%)				1
10	2 (100%)				1
11	3 (100%)				1
12	4 (100%)				1
13	5 (100%)				1
Total number of cases and siblings	76	96	38	1	211 (51 families)

#### 4.2.4 Size of family

Parents have previously reported that large families make keeping up to date with immunisations logistically difficult (3). This was also reported by parents during this outbreak – some parents noted a lack of time for immunisations due to large families. During a previous outbreak in this same community, the Health Protection Team’s experience was that larger families are often not vaccinated (5).

In this outbreak, the largest family had 13 children. Figure 5 shows the sizes of families of the cases reported to the HPT.

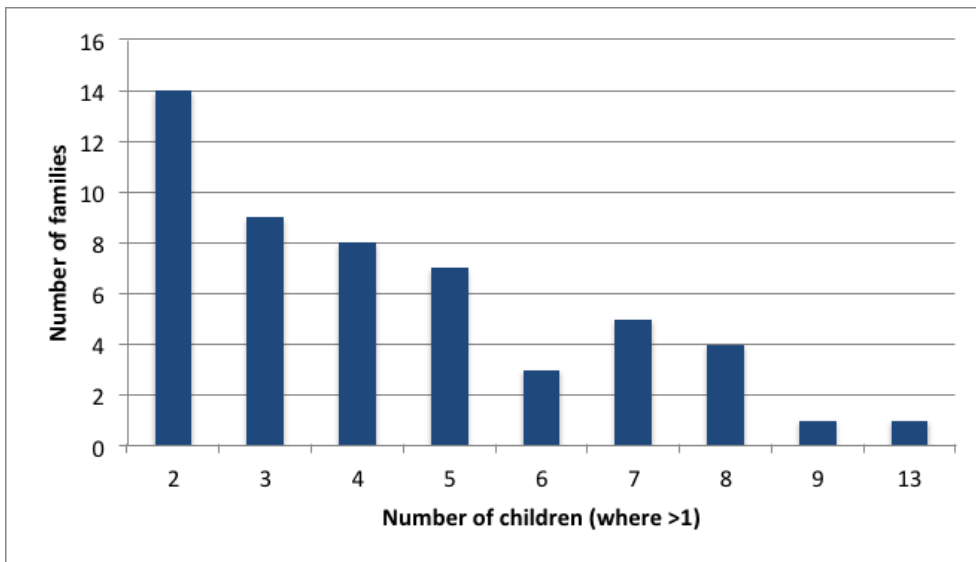


Figure 5: Sizes of families of cases

Tables below show vaccination status by number of children in family. Table 10 shows data for families not known to be reluctant in vaccinating their children and table 11 shows the data for families who have clearly expressed their reluctance to vaccinate their children (see section 4.2.2). This data includes children too young to be vaccinated, but this is not shown in the tables below.

The proportion of fully vaccinated children is highest in families with 5 children and lowest in families with two children. This is somewhat surprising as the birth order analysis suggests that as birth order (and so the number of children) increases, the likelihood of being fully vaccinated tends to decrease, therefore we would expect smaller families to have more children who are fully vaccinated. Yet, this analysis does not suggest this.

Table 10: Vaccination status by number of children in the family – for families not known to be reluctant to vaccinate

Number of children in the family	Fully vaccinated (including fully for age)		Not vaccinated		Partly vaccinated		Not known		Total Number of Cases	Number of families
	Number	%	Number	%	Number	%	Number	%		
13 children	13	100%							13	1
8 children	11	35%	15	48%	5	16%			31	4
7 children	10	36%	10	36%	5	18%	1	4%	28	5
6 children			2	29%	5	71%			7	2
5 children	22	61%	4	11%	5	14%	1	3%	36	7
4 children	7	25%	12	43%	8	29%			28	8
3 children	9	47%	5	26%	2	11%			19	7
2 children	4	15%	8	31%	8	31%			26	13
Grand Total	76	40%	56	30%	38	20%	2	1%	188	47

It is not possible to draw any conclusions from this analysis for a number of reasons

- In a two-child family, at least one child will be the case, which means at least one child (50%) will have only one dose of MMR (partially vaccinated or fully vaccinated for age) or no doses of MMR (not vaccinated or too young), therefore reducing the % of fully vaccinated children in a two child family (and smaller families in general) relative to larger families.
- The size of families of cases in this outbreak does not necessarily represent the size of families in the community, that is, we have no denominator to be able to calculate a true rate of vaccination by family size.

- Although the analysis includes 188 cases and siblings, they belong to 47 families and the vaccination status of children in families will be correlated therefore this number of families may be too small for this analysis
- Similarly, as the family size increases, the number of families decreases and the vaccination status of the cases and siblings is correlated therefore we would expect clustering of vaccination status
- For many families, the full list of children in the family and/or their vaccination status was not known and so they were excluded from analysis. It is quite possible that this missing information is biased towards larger or smaller families making analysis unreliable.

Therefore, another method of analysis needs to be used or it is not possible to look at the effect of size of family from the data available.

Table 11: Vaccination status by number of children in the family – for families reluctant to vaccinate

Number of children in the family	Partly vaccinated		Not vaccinated		Too young		Total number of cases	Number of families
	Number	%	Number	%	Number	%		
9 children			9	100%			9	1
8 children			1	100%			1	1
7 children			6	86%	1	14%	7	2
6 children			11	92%	1	8%	12	2
4 children			4	100%			4	3
3 children			8	100%			8	3
2 children	1	33%	2	67%			3	1
Grand Total	1	2%	41	93%	2	5%	44	13

Families who clearly expressed a reluctance to vaccinate their children, unsurprisingly, had no children who were fully vaccinated and most children were unvaccinated and the size of the family shows not impact on vaccination status (Table 11).

### 4.3 Data quality

The use of routine data has the advantage of saving time and resources in collection of data and HP Zone records are a rich source of data on vaccination of children in the household and family beliefs about vaccinations. Records are made contemporaneously so data is available as soon as it is entered and there is a record of changes made. All records made related to this outbreak were available at the time that they were retrieved for this analysis.

However, HP Zone is a case management system and the recording of information required for clinical and public health management is prioritised. Additionally, case management and therefore data entry was by multiple people who, despite standard protocols, would have differed in the way that they asked for and captured data. Therefore, the information that would have been helpful for this paper was not always recorded or not recorded in a systematic way. This must be borne in mind when interpreting the evidence presented in this paper. In particular,

- Demographic data on cases was always recorded, as this is essential for case management.
- As information on the MMR vaccination status of cases is crucial for initial risk assessment and categorisation of the diagnosis into possible and probable (public health action is only taken for probable and confirmed cases), this information was always recorded in HP Zone, although not always in the designated section. HP Zone has a specific section of the database where vaccination with respect to



diagnosis can be captured as well as reasons for no vaccinations. This data can also, and often was, recorded in the free-text record of chronological events.

- Quality of information on contacts was variable. Whilst the number of household and relevant (vulnerable) non-household contacts and their immunisation status was generally always recorded (required for case management purposes), full details of all contacts were not always captured unless required for clinical follow up. Contacts were not always added to HP Zone as separate records. In many cases, demographic and immunisation information about the contacts was captured in events. Additionally, there was evidence of errors in recording of some details e.g. two children from the same family with dates of birth only a few months apart. Such errors are likely to be minimised for cases but not necessarily for contacts.
- The information on vaccination history of contacts was either taken from parents or health care workers (most often from GP records). Recall of vaccination history by parents or cases can often be unreliable. There were multiple instances where the parents' recall of vaccination history was proven unreliable when clinical data was obtained. Especially for non-vulnerable contacts, who did not need follow up as per guidance, vaccination status was not always collected.
- Documentation of reasons for incomplete or no vaccination history were often poorly completed. Whilst a discussion of whether the case and contacts were immunised was nearly always conducted, there was often no record of a discussion about why children were unimmunised.
- There is evidence from the notes that some cases were not reported to the Health Protection Team because they did not present to GPs or other healthcare services. Therefore it is very likely that not all cases were recorded and the outbreak was larger than documented.
- It is possible that the accuracy and comprehensiveness of the data was reduced during the peak of the outbreak because of the increase in workload.

## 5. Discussion

The 2012/13 outbreak in the North East London Charedi community resulted in a large number of cases notified to the HPT between December 2012 and August 2013. The 143 cases came from 94 families. The outbreak was driven by lack of vaccination those old enough to be fully vaccinated. Over half the cases (57%) could have been fully protected against measles but were not. Even in the age group that could have received at least one vaccination (14 to 40 months), the majority (83% of this age group) were completely unvaccinated. 17% of the cases were too young to be given any vaccinations. Given the high efficacy of the vaccination, increased levels of vaccination would have undoubtedly resulted in fewer cases in the older age group and therefore fewer cases in the under 40 months age group. The majority of the siblings of cases who were not cases themselves were also unvaccinated (60%). However, it is highly likely that quite a few of these siblings were not susceptible because of previous exposure and infection. Therefore, it was not possible to work out the attack rate in households and the community.

Nearly a third of the cases (n=56, 21 families) were in families who expressed reluctance in vaccinating their children. Cases in these families were almost all due to no vaccination in children eligible for two doses of MMR. Even in families that did not express negative beliefs about vaccinations, numbers of unvaccinated or partly vaccinated individuals was high.

Twenty-one of the 94 families did not vaccinate due to various fears about the vaccination. Low rates of vaccinations in other families who did not specifically express reluctance to vaccinate were due to confusion about the children's vaccination status and lack of time, particularly due to large families. It should be noted that this information was only available for 25 of 68 families who could have vaccinated their children but did not. There was no record of a discussion with 18 families.

None of the families cited religious beliefs as being a reason for not vaccination.

There was some suggestion of less than full engagement with NHS provided healthcare by some families but there was little suggestion of access to healthcare being a barrier to vaccination, as suggested in some studies. Some families, possibly more than the HPT were aware of, were registered with private GPs and this may itself be a barrier to engagement with NHS driven campaigns.

An attempt was made at quantitative analysis to test the theories put forward by earlier studies and to support qualitative data. Plotting vaccination status by birth order suggested that older children in the family were more likely to be vaccinated than younger children, that is, birth order was negatively associated with fully vaccinated status. It was not possible to support or refute this by analysing vaccination rates by family size due to the lack of data to complete a robust analysis. Other UK studies have suggested that living in a household with other children increases the risk of the child being unvaccinated with MMR (15). Data on birth order and size of families was not available for all cases (51 of 94 families and 211 of the total 305 cases and siblings).

The data in this analysis is from 2012/13 and was driven by historic lack of vaccination in the cohort. Given the lag time between the lack of vaccination and the outcome, it is important to be careful about using the data to make assumptions about current vaccination rates. However, the information on parents' attitudes of vaccination is recent (collected during the outbreak in 2012/13). This suggests that the focus of any new intervention should not just be on the new cohort of children requiring vaccination but on catch up in the historic cohort of children who should have had vaccinations but did not.

### 5.1 Limitations of the analysis

- It is not possible to say whether the cases and their families are representative of the Charedi community in North London and how the Charedi community might differ from other populations
- Data on measles vaccine coverage for the Jewish communities is not available so it is not possible to be certain that vaccination rates in this community are lower than the rest of the community (which is one of the assumptions of this analysis and the Tailoring Immunisations Programme) but there is evidence of lower uptake than the required 95 per cent from COVER data from GP practices that serve this community as well as the repeated outbreaks in the community.
- Full analysis of some of the data was not possible because of a lack of denominator data
- There is the potential for bias in the analysis, particularly in the way that the data was missing. There was no information on reasons for lack of vaccination for 18 families and data for birth order and size of family analysis was only available for 51 of the 94 families. The other families either only had one child or lacked information on number of children and/or their vaccination status. It is possible that this missing data was not missing at random. Larger families may be more likely to have data missing on the whole family because of the increased workload of hanging to collect this information. It may be that the families with no information in notes about reason for lack of vaccination or access to healthcare were difficult to talk to because of reluctance to engage which may also make them reluctant to vaccinate.
- There is a possibility in recall bias of vaccination status. This is particularly true for the siblings who were not infants, as the HPT would not have required precise clinical information for case management. Parents may have said children were vaccinated when they were not in order to avoid conversations about vaccination.
- The quality of data collected on non-case siblings was not as good as that available for cases. This has been noted in section 4.3.
- There are other factors that influence vaccination uptake e.g. socio-economic status and organisation of immunisations services. It was beyond the scope of this project to identify and control for these.

## 6. Possible Interventions to increase immunisation uptake

From the findings of this analysis and considering that catch up is as important in prevention build up of susceptible populations as new cohorts, the following interventions are proposed.

- Midwives and GP practices use maternity and new baby checks to discuss vaccinations in older children and vaccinate or issue reminders as necessary (Making Every Contact Count). Given the large family sizes and the possibility that as families have more children they are less likely to be vaccinated, the contact with health care services during a new pregnancy and after the birth of a new baby may be opportune times to review vaccination for all children in the family and renew discussions about vaccination.
- Parents with larger families are identified and given additional support, possibly in the form of nurses that vaccinate at home or GP practices making access easier.
- Parents are supported in identifying when their children are not immunised. An annual health review of families may help with this (in a similar way to annual review of people with Long Term Conditions).
- Negative beliefs about vaccinations held by the community are addressed, recognising that they appear to be driven by fear of vaccine and lack of engagement with healthcare services.
- Use of private GPs and their influence on the vaccination rates in the community is assessed. Any efforts to improve uptake by the NHS services may not reach some families because of their lack of engagement with the NHS.
- Surveillance and reporting of notifiable diseases is improved. There was evidence of lack of reporting or late reporting of measles case, which means a delay in control measures.
- Health Protection team/ local public health teams/GPs take all discussions with cases/parents of cases of vaccine preventable disease as opportunities to explore health beliefs about vaccination and document this (Making Every Contact Count).

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## Appendix 1

Reasons given by families for not vaccination (12 families definitely or possibly reluctant to vaccinate where reasons for reluctance are recorded)

### *Medical Advice*

Family 66- "received first dose (may only have been DTP, mum couldn't remember), but then on medical advice has had no further imms. No MMR."

### *Chooses to wait until child is older*

Family 67 – "mother prefers to wait until child is 2"

### *Does not believe evidence*

Family 35- "[Mother] said she does not believe in MMR and hence none of the children are immunised. But all the sibling had measles in the last months."

### *Does not engage with health services*

Family 58 – "[Mother] does not tend to use health services. GP not aware of her being unwell."

### *Fear of vaccine*

Family 11- "[Case] received her first 2 infant vaccines, but her mother believes that they gave her pertussis, which she believes now recurs every year in winter."

Family 34- "parents made a conscious decision not to give any as they didn't think the vaccines are safe."

Family 97- "She is concerned about vaccination, the risks and feels that natural infection is better than vaccines. She has researched this."

Family 48- "Father and mother have very strong feelings against MMR. Concerned about risks of vaccine vs. risks of infection. Also two family cases of autism shortly after given MMR. Talked through risks and research to date, issues with onset of autism timed with MMR etc. He had very fixed ideas and I was not able to change his mind."

Family 12- "Case was not vaccinated (older sibling had bad reaction to MMR)"

Family 81- "She asked if single vaccines are available and I said they are not in the UK and the evidence showing problem with MMR has since been shown to be flawed."

Family 90- "He has not had any MMRs due to allergies and parental decision not to vaccinate."

### *Prefers natural infection*

Family 36- "She is apprehensive about vaccination, preferring for her children to have natural infection - discussed this at length and she will discuss in time perhaps with her GP again."

Family 1- "Discussed with mother. Not immunised as mother prefers natural treatments. Importance and safety of MMR discussed, with a focus on Rubella. I suggested she look at NHS immunisation site (she has internet access) and to discuss with the surgery further."



April 2015

Dear Doctor

**Seeking your practice's engagement: Investigating barriers and facilitators relating to immunisation within the Charedi community**

I write to ask if your practice would consider taking part in a local study seeking to explore barriers and facilitators influencing children's immunisation within the local Charedi community. We are asking local practices to make short questionnaires available for Charedi parents and carers with one or more child under the age of 6 years. In London, we are working in collaboration with NHS England and members of the Charedi community.

This has three parts:

1. Questionnaire study: I enclose the questionnaire which has, along with the methodology, been approved by the national Research Ethics Committee. We would like these to be made available over a 3 week period in both GP practices and also local Children Centres.
2. In-depth parent interviews: These will be undertaken with willing parents or carers identified through the questionnaires, exploring emerging themes from the questionnaires. The interviews are to be conducted in collaboration with colleagues from the London School of Hygiene and Tropical Medicine.
3. Detailed analysis of existing data sources including measles epidemiology and documented reasons for non-vaccination in children notified to have suspected measles.

If your practice is willing and able to be involved, and make questionnaires available over a three week period, I would be grateful if you could contact me on the above telephone number, or by e-mail ([Vanessa.rew@phe.gov.uk](mailto:Vanessa.rew@phe.gov.uk)) as soon as possible. I will then ask you to then sign a form for local ethics approval, which states that you agree that your practice is happy to participate.

We can visit your practice to talk to staff about the importance of this work, deliver hard copies of the questionnaire (also available in Yiddish and Hebrew) and leave a collection "post box" for completed questionnaires.

Thank you for considering supporting this piece of work.

Yours sincerely

Vanessa Rew  
Nurse Consultant

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## Tailoring Immunisation Programmes

The Guide to Tailoring Immunisation Programmes (TIP) aims to help countries across Europe at national or sub-national levels to shape strategic responses to immunisation programming and communications. In doing so, the Guide considers immunisation of infants and children as a positive care-giving practice, with important community and social benefits.

The overall objective of the Guide to TIP is to provide proven methods and tools that can help national immunisation programmes design targeted strategies that increase uptake of infant and child vaccination, thereby increasing immunisation coverage rates and curbing the risks of vaccine preventable diseases (e.g. measles).

Locally, within Hackney and Haringey, the work will aim to provide tools which:

1. Identify and prioritise any particularly susceptible populations within the Charedi community
2. Diagnose the demand and supply side barriers to immunisation:
  - a. Guide a detailed level of understanding as to what drives caregiver's immunisation practices
  - b. Explore the role that immunisation providers play in influencing caregiver's immunisation choices and actions.
3. "Prescribe" evidence-informed responses:
  - a. Guidance for designing, implementing, monitoring and evaluation of recommended "solutions" based on research findings, segmentation and profiling of the target population
  - b. Drawing on the experiences and insight of other programmes and projects in Europe and the USA for Charedi communities to identify best practice.

### Reference:

World Health Organization (2013) *Guide to Tailoring Immunization Programmes*. Available at:

[www.euro.who.int/\\_data/assets/pdf\\_file/0003/187347/The-Guide-to-Tailoring-Immunization-Programmes-TIP.pdf](http://www.euro.who.int/_data/assets/pdf_file/0003/187347/The-Guide-to-Tailoring-Immunization-Programmes-TIP.pdf)



## Please tell us about children's immunisations in your community

We are exploring factors that encourage or prevent you from immunising your children. If you are a parent or guardian of a child aged less than 6 years, we would really welcome your views. All responses will be reviewed and compiled in a report for the community and those who commission and provide the service. We can send the report to you if you add your details to the final page.

If you do not wish to complete this questionnaire, please just say so when you are approached with this form.

Responses are completely anonymous, unless you choose to provide your details on the final page. If you do this, your contact details will be stored confidentially. All answers will be stored in our secure system.

<b>1. Are you the parent or a guardian of one or more children aged under six years?</b>	<input type="checkbox"/> <sub>1</sub> Yes	<input type="checkbox"/> <sub>2</sub> No			
<i>If 'no', thank you for your time but you don't need to complete the survey as we are only looking for the views of parents or guardians of children under 6 years of age.</i>					
<b>2. What age are you?</b>	<input type="checkbox"/> <sub>1</sub> 16-19 years	<input type="checkbox"/> <sub>2</sub> 20-24 years	<input type="checkbox"/> <sub>3</sub> 25-29 years		
	<input type="checkbox"/> <sub>4</sub> 30-34 years	<input type="checkbox"/> <sub>5</sub> 35-39 years	<input type="checkbox"/> <sub>6</sub> 40 years +		
<b>3. What is your gender?</b>	<input type="checkbox"/> <sub>1</sub> Female	<input type="checkbox"/> <sub>2</sub> Male			
<b>4. How many children aged under 6 years live with you?</b>	..... Please write in number				
<b>5. Are all these children up to date with their immunisations?</b>	<input type="checkbox"/> <sub>1</sub> Yes Please go to Q6	<input type="checkbox"/> <sub>2</sub> No Please go to Q7	<input type="checkbox"/> <sub>3</sub> Not sure		
	<input type="checkbox"/> <sub>1</sub> I want to protect my child from illness	<input type="checkbox"/> <sub>2</sub> I know a child who was ill from a vaccine preventable disease eg measles			
<b>6. If, yes, please give reason(s) for choosing to immunise? Please tick all that apply</b>	<input type="checkbox"/> <sub>3</sub> I believe vaccination is important to prevent spread of disease in the community	<input type="checkbox"/> <sub>4</sub> Health Professional recommendation			
	<input type="checkbox"/> <sub>5</sub> Friend or family recommendation	<input type="checkbox"/> <sub>6</sub> Community member recommendation			
	<input type="checkbox"/> <sub>7</sub> The facilities at the immunisation clinic were child friendly	<input type="checkbox"/> <sub>8</sub> It was easy to get an appointment			
	<input type="checkbox"/> <sub>9</sub> Other (please provide details below)				
<b>Please provide any additional suggestions/comments</b>	Please go to Q8				
<b>7. If 'No' please give the reason(s) for the child(ren) not being up to date with their immunisations?</b>					
<b>8. How helpful do you think the following suggestions would be in improving immunisation services for the Charedi community?</b>					
	Not helpful	Slightly helpful	Moderately helpful	Quite Helpful	Very Helpful
a) More vaccination sessions at children's centres	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>



b) More vaccination sessions in community locations <i>E.g. community halls, shopping centres etc.</i>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
c) Sunday appointments	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
d) More after school appointments	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
e) More child-friendly facilities in General practices/Health Centres <i>Eg; access or secure parking for buggies, play area for children, baby changing facilities etc</i>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
f) Shorter waiting time	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
g) More fixed appointments rather than 'drop-in' clinics	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
h) More drop-in clinics rather than fixed appointments	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
i) Home visits	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
j) Text reminders for appointments	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>

Please provide any additional suggestions/comments

### 9. Where would you usually go for advice on vaccination?

General Practice / Doctors surgery <input type="checkbox"/> <sub>1</sub>	Children's centre <input type="checkbox"/> <sub>2</sub>	Friends/family <input type="checkbox"/> <sub>3</sub>	Health visitors <input type="checkbox"/> <sub>4</sub>	Community newsletters <input type="checkbox"/> <sub>5</sub>	Other <i>Please specify</i> <input type="checkbox"/> <sub>6</sub> .....
--	--	---	---	---	---

### 10. How satisfied were you with the information provided?

Completely dissatisfied	Slightly dissatisfied	Neither satisfied nor dissatisfied	Slightly satisfied	Completely satisfied
<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>

### 11. How helpful do you think the following suggestions would be in improving the immunisation information provided to the Charedi community?

	Not helpful	Slightly helpful	Moderately helpful	Quite Helpful	Very Help ful
a) More information on benefits and risks of vaccination	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
b) Community 'Champions' <i>ie. People within the Charedi community whom you could approach for information and advice</i>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
c) More information on immunisation provided in community newsletters	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
d) Community immunisation advice line	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>
e) Charedi nurses providing immunisation service	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>

Please provide any additional suggestions/comments

Thank you for completing this questionnaire

Yes, I would like to receive a copy of the final report from this study

*We will be running a series of interviews to discuss the issues that arise from the questionnaire responses. If you are interested in further helping to shape immunisation services in your community and would like to be included in these discussions please indicate below:*

Yes, I am willing to be contacted about taking part in interviews to help improve immunisation services within the Charedi community

If you have answered yes to either of the points above, then please provide contact details below:

### Contact details

<b>Name:</b>	
<b>Phone:</b>	
<b>Mobile:</b>	
<b>Email:</b>	
<b>Instructions</b>	<i>E.g. preferred method of contact or best day or time to call</i>

**Anonymous:** If you wish your questionnaire responses to remain anonymous, remove this final page and return this sheet *separately* to the receptionist (if given to you in a GP surgery or Children's Centre) or by post to:

North East London Health Protection Team  
Ground Floor, South Wing  
Fleetbank House  
2-6 Salisbury House  
London  
EC4Y 8JX

**Alternatively, you can contact us on:**

E-mail: [necl.team@phe.gov.uk](mailto:necl.team@phe.gov.uk)

Telephone: 020 3837 7084

**Version 3.0**

## Charedi parents' questionnaire survey

To explore reasons for lower immunisation uptake and find out what would improve the immunisation experience for parents/carers a questionnaire survey (Appendix x) was designed using the SWOT analysis as a guide. Stakeholders and community members including the lead rabbi contributed to the design. Hebrew and Yiddish translations were available. Additionally parents were asked to provide their contact details if they were interested in being involved in a qualitative interview study.

Questionnaires were distributed via general practices and children's centres. One hundred and twenty-six questionnaires were returned from six locations between June and September 2015. Of these, 43 had children were not up-to-date with their immunisations, 4 were unsure of their children's vaccination status, and 78 had children who were up to date with their immunisations, (1 respondent left this field blank). Only 3 responders had 5 or 6 children younger than 6 years of age, so these categories were combined with those having 4 such children. None of the responders had more than 6 children.

Questions relating to service evaluation and improvement included:

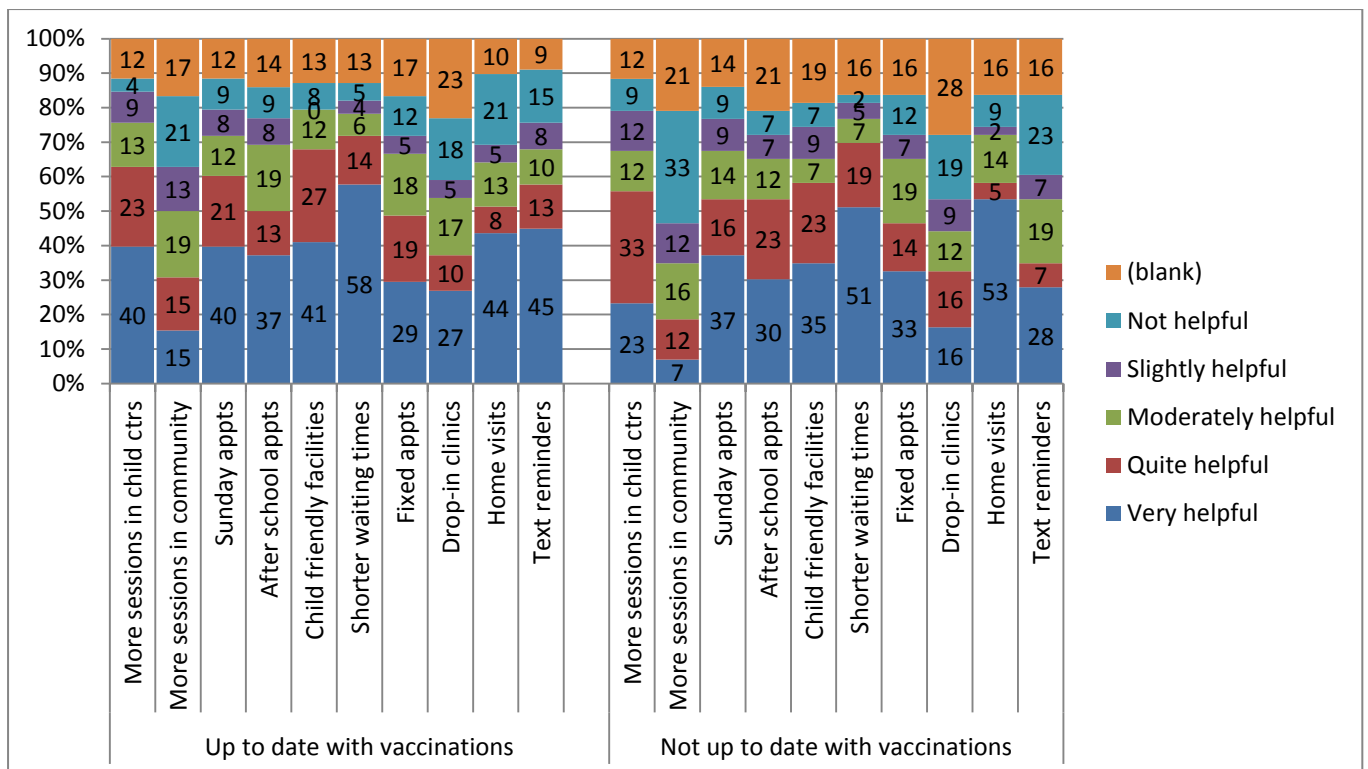
### How helpful would the following be to improve services?

Respondents were asked to indicate how helpful they thought each option relating to immunisation service improvement would be (Fig X below).

**Shorter waiting times** would be the most popular service improvement with around 70% of respondents reporting this as helpful or very helpful. The next favourable options were **child friendlier services** (64%) and **more immunisation sessions run in children's centres** (60%). **Sunday appointments** (58%) and home visits (54%) followed. Families with one child or two children had higher odds of finding it more helpful to have Sunday appointments.

**Text reminders** of immunisation appointments were seen as a helpful or very helpful service improvement by over half of those whose children were up to date with their appointments compared to a third of those whose children were not up to date. Interestingly, those parents that had a large number of children, their odds of finding text message appointment reminders "very helpful" were low. NB: This is adjusted for age, so there is something else that would explain this (not just age of parent).

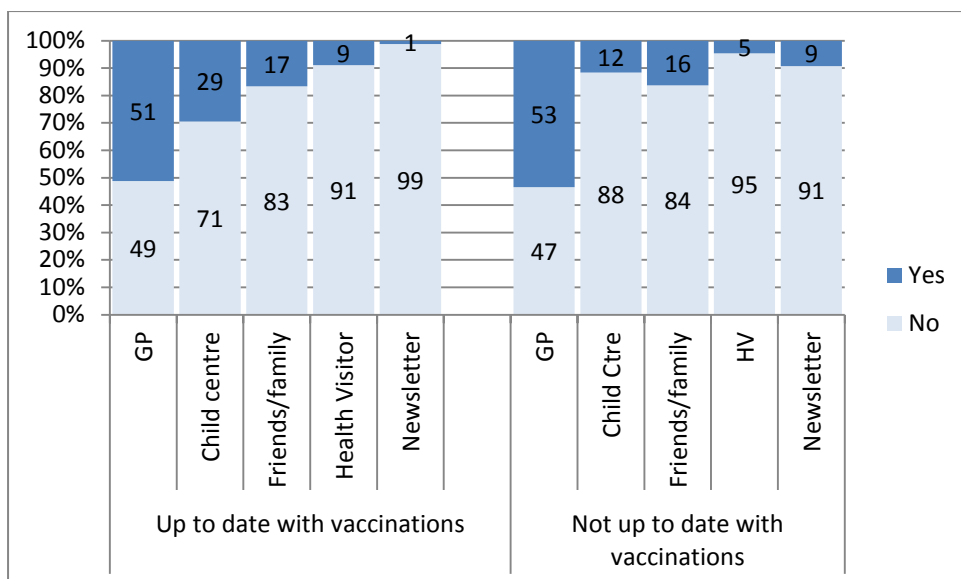
Sessions in community locations (e.g. community halls and shopping centres – excluding children's centres) was the least favourable of all listed.



**Fig. X** Community questionnaire response to the question “How helpful would the following be to improve services?” according to level of perceived helpfulness, and respondents divided into those whose children were or were not up-to-date with vaccinations.

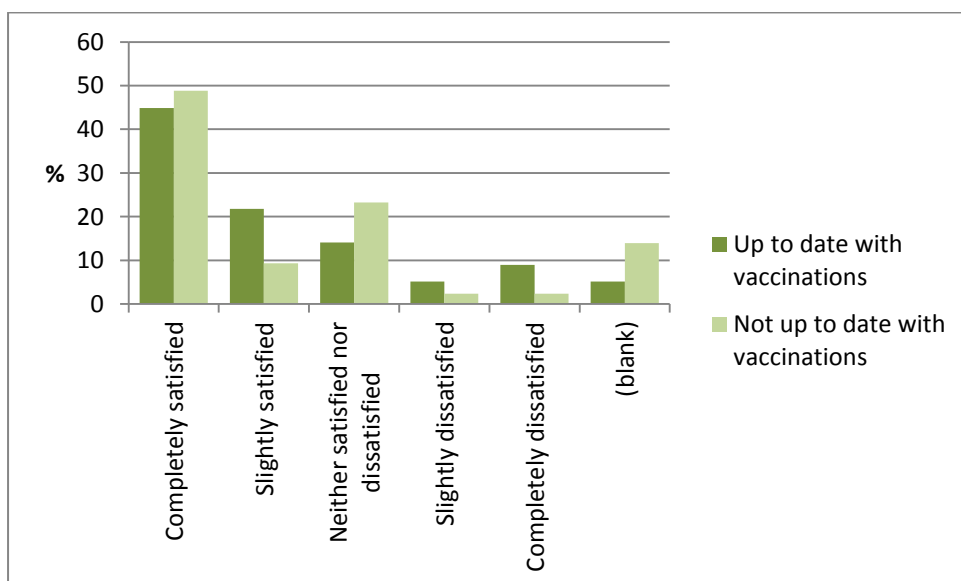
### Communication and knowledge

Respondents were asked where they would usually go for advice on immunisations, and how satisfied they were with the information received. GPs were the most popular source of information for both those whose children were and were not up-to-date to immunisations. Almost a third (29%) of respondents whose children were up-to-date also sought advice from Children’s Centres, compared to just 12% of those whose children were not up-to-date. Newsletters were cited as a more popular (9%) source of advice for respondents whose children were not up-to-date, compared to those whose children were up-to-date (1%). The usual content of immunisation advice within these newsletters is unknown.



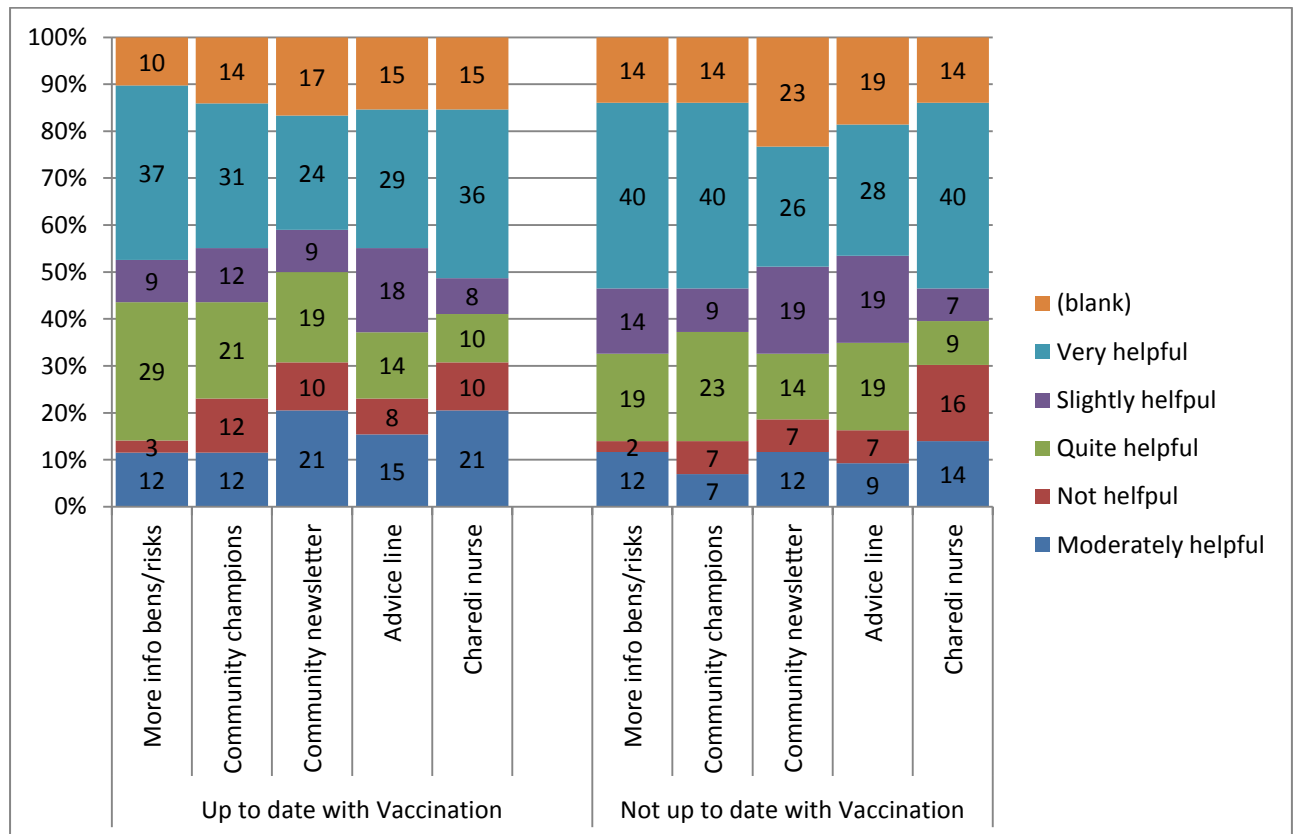
**Fig. X** Community questionnaire response to the question “Where would you usually go for advice on immunisations?”, split into respondents whose children were up-to-date and not up-to-date with vaccinations.

Over 40% of both sets of respondents (those whose children were up-to-date (45%) and those whose were not (49%) stated that they were completely satisfied with the information provided to them. More respondents whose children were up-to-date (9%) stated that they were completely dissatisfied or slightly dissatisfied (5%) with the information provided to them, compared with just 2% of respondents whose children were not up-to-date being completely dissatisfied and 2% slightly dissatisfied. These results highlight that more than half of all parents / carers are not completely satisfied with the immunisation information available to them (see Fig X below).



**Fig. X** Community questionnaire response to the question “How satisfied were you with the information provided on immunisations?” (%), according to whether the respondent’s children were up-to-date or not with vaccinations.

Respondents were also asked how helpful they thought various suggestions for improving immunisation information provision would be for the community (Fig X). There was little difference in the perceived helpfulness of each of each proposed intervention between the two respondent groups. Those considered the most helpful was more information on benefits and risks, community champions for immunisations and having a Charedi nurse. There is some evidence of association between age and helpfulness of more information on benefits and risks, with 25-29 year old age group having higher odds of finding it more helpful compared to 20-24 year old age group (OR = 2.35 (95% CI: 0.77 – 7.21)) although it is not significant at the 5% level.



### What can we learn about those families whose children are *up-to-date* with their immunisations?

#### PHE/NHS Parent / carer questionnaire:

For those families who were up-to-date with their immunisations, the most commonly selected reasons given were protection from illness and important to prevent spread of disease by 63 (53.9%) and 52 (44.4%) individuals, respectively. Health care

professional recommendation (25%), facilities child friendly (n=17), friend or family recommendation and easy to get appointment (13 each) were the other reasons selected by 10 or more parents. Sixty respondents (51.3%) selected general practice as preferred venue for advice on vaccination, while children's centre and family/friends were chosen by 29 (24.8%) and 18 (15.4%), respectively. Fewer than 10 respondents selected any other venue.

### What can we learn about those families *delaying* childhood immunisations?

The questionnaire had free text boxes enabling parents to comment on reasons for delaying or refusing immunisations. The numbers were small but include reasons based either on reported or perceived "bad experiences" of children's immunisations, or a mistaken belief that delaying immunisation will protect the child's immature immune system.

*"Bit nervous to immunise as special needs"*

*"I have had a negative experience regarding immunisation and I would not do it at a young age"*

*"I have heard interviews with doctors on a telephone hotline, where experienced practitioners have seen over years of practice that thousands of parents have reported that they have seen a decrease in development of their infants/toddlers after vaccinations. I do not want to take risks and I therefore give vaccinations when my kids are older than they recommend or decline for now until I feel they are strong enough"*

*"I'm not immunising my child as she is still very young and therefore her kidneys have not finished developing, etc."*

*"I only start it after breast feeding"*

*"I give injections to my children unless they are sensitive with allergies. In that case I prefer to wait till they outgrow it. I have acquaintances who have personally had negative experience with very young children"*

*"Our baby had a severe reaction after each of triple - ending with months of very loose stools and really unwell until we finally managed to control with alternate treatments"*

### What can we learn about those families *refusing* childhood immunisations?

Reasons for refusal were diverse, including a negative experience, unwillingness to put their child through the pain of being immunised, concern that their child has had a previous illness, informed side effects and also a perception that information on side-effects is intentionally being withheld:

*"Don't give. I had encephalitis twice as a child  
from MMR"*

*"I don't want to put my child through pain! Not  
sure if it's the right thing to do still researching"*

*"I believe there is something regarding the  
MMR injection! A family member was ill from  
this"*

*"After hearing from professionals that my older children were immunized might have  
behavioural difficulties because of the immunizations that they had, I was apprehensive to  
continue giving them.*

*Also on the bottle of immunization are there side effects written that I'm not told about?"*





## Protocol

### Study title:

Parental views of the childhood immunisation programme in the London Charedi orthodox Jewish Community: An in-depth qualitative analysis

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## A. Background

### 1. Tailoring Immunisation Programmes

The Guide to Tailoring Immunization Programmes (TIP) was developed by the European office of the World Health Organization to provide proven methods and tools to assist national immunization programmes in diagnosing enablers and barriers to vaccination in any population<sup>1</sup>. TIP provides tools to identify susceptible populations, determine barriers to vaccination and implement evidence-based interventions. The approach draws on health programme planning models, including the medical humanities, the social and behavioural sciences. TIP is intended for use by healthcare professionals, public health authorities and decision-makers and may be particularly valuable where pockets of low vaccination coverage or increased susceptibility to VPDs are identified.

The implementation of TIP methodology is being explored in north London, within the Charedi community, in which sub-optimal immunisation coverage is known to result in persistent outbreaks of vaccine-preventable diseases (VPDs). The background and current context relating to immunisations and VPDs in the community, justification for implementing TIP methodology and the outcomes of preliminary consultation meetings are given below.

### 2. The Charedi community, north London

Orthodox Judaism refers to strictly observant Jews, the most well-known being the *Hassidic* community. The title *Hassid* means “The Righteous One(s)”, and describes a movement beginning in Poland in the 17<sup>th</sup> century which spread throughout Eastern Europe with many living in rural and secluded lifestyles insulated from the outside world<sup>2</sup>. Following the Holocaust, the remaining *Hassidic* communities settled around the world including the USA, UK and Belgium. The *Hassidic* Orthodox Jewish community based in the London boroughs of Hackney, Barnet and Haringey (north east and central London) is the largest in Europe. A 2011 study in Hackney identified that the community comprised 7.4% (17,587) of the population of the borough<sup>3</sup>. The adjoining borough of Haringey was estimated to have approximately 2,844 Charedi residents in 2013<sup>4</sup>. It is notable that the neighbouring borough of Barnet is home to the highest proportion of Jewish residents in England, however, only a small proportion are known members of the Charedi community<sup>5</sup>. Anecdotally it is reported that approximately 25 infants are born into the London Charedi community each week, which results in a 4% population increase year on year. As such, the Charedi population is highly skewed towards children and average household sizes are much larger than the Hackney

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<sup>1</sup> World Health Organisation (2013) *Tailoring immunisation programmes*. Available at:

[http://www.euro.who.int/\\_data/assets/pdf\\_file/0003/187347/The-Guide-to-Tailoring-Immunization-Programmes-TIP.pdf](http://www.euro.who.int/_data/assets/pdf_file/0003/187347/The-Guide-to-Tailoring-Immunization-Programmes-TIP.pdf)

<sup>2</sup> Spitzer J. 2005. *A guide to the Orthodox Jewish way of life for healthcare professionals*. Third Edition: Senprint

<sup>3</sup> Mayhew L, Harper G and Waples S. July 2011. *Counting Hackney's population using administrative data - An analysis of change between 2007 and 2011*. Available at: <http://www.hackney.gov.uk/Assets/Documents/estimating-and-profiling-the-population-of-hackney.pdf>

<sup>4</sup> Harper G, Mayhew L, and Waples S. December 2013. *Using administrative data to describe and estimate the local population*. Available at: [http://www.haringey.gov.uk/haringey\\_report\\_final\\_december\\_13.pdf](http://www.haringey.gov.uk/haringey_report_final_december_13.pdf)

<sup>5</sup> Institute for Jewish Policy Research. April 2011. *Key trends in the British Jewish community: A review of data on poverty, the elderly and children*. Available at: <http://www.jpr.org.uk/documents/Key%20trends%20in%20the%20British%20Jewish%20community.pdf>

average. The population is thought to double in size every 15 years, and as such, demand on services including health will continue to increase.

Since April 2013, childhood immunisations in England have been commissioned by NHS England. In the London borough of Hackney, they have been provided by the Homerton University Hospital NHS Foundation Trust. Various models of immunisation delivery have been provided for the community in north London, seeking to complement the traditional (national) model of immunisation through general practice. This has included the introduction of community immunisation clinics, the employment of a Charedi outreach nurse, home immunisation (restricted) and school based clinics during a measles outbreak. Information regarding childhood immunisations and the diseases prevented by them was produced in a leaflet translated into Hebrew and Yiddish. Health columns and adverts in the local Jewish press have also been used to promote immunisations and advertise local immunisation clinics.

Routine immunisations within the school setting (e.g. the teenage booster) have not been delivered to the majority of Charedi children and teenagers since many attend independent schools. The HPV vaccination for teenage girls is also not delivered to the community through schools. Reasons for this include logistics and lack of demand.

The monitoring of and response to notified VPDs across north east and north central London is the responsibility of the north east and north central London Health Protection Team (NENCL HPT). This is a local office of Public Health England (PHE), an executive agency of the Department of Health with the mission of protecting and improving the nation's health and addressing inequalities.

### 3. Immunisation coverage and associated factors

Recurrent outbreaks of VPDs in the north London Charedi community indicate sub-optimal coverage of immunisations. Practice level data indicates reduced coverage in those with high proportions of Jewish patients. However, since membership of the Charedi community is not captured on any routine health records practice level immunisation coverage offer the best estimate of Charedi community immunisation cover (see Figure 1 below). A 2011 survey found that three GP practices in the north of Hackney had between 41-78% of patients stating they were Jewish<sup>6</sup>. Certain practices (including these three), located in north Hackney and likely to serve the Charedi community, have lower vaccination coverage rates than other practices serving the rest of the population (refer to Table 1 below). Across the borough border in Haringey, a 2013 Health Equity Audit regarding childhood immunisation in 2011-2012 noted similar uptakes across all ethnic groups *with the exception* of those residents identifying themselves as being Jewish. There was a significantly lower uptake in children (across all vaccination targets) identified as Jewish living in the South Tottenham ward, most notably within Seven Sisters<sup>7</sup>.

Studies within Orthodox Jewish communities in other countries have indicated lower coverage in comparison to the non-Orthodox Jewish population, such as in Antwerp, Belgium where a 4-fold lower chance of complete vaccination was identified in children from the community, together with an

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<sup>6</sup> Health and Wellbeing Profile (2011-12). Available at: <http://www.cityoflondon.gov.uk/services/adult-health-wellbeing-and-social-care/doctors-dentists-and-hospitals/Documents/health-and-wellbeing-profile-2011-12-part-two.pdf>

<sup>7</sup> Haringey Public Health Directorate (2013). *Children receiving the recommended childhood vaccinations 2011-12*. Unpublished

increase in temporal spacing<sup>8</sup>. In the absence of coverage data in the UK, the recurrent outbreaks of vaccine preventable diseases suggest sub-optimal coverage.

**Table 1.** Performance data (%) from a selection of practices based in North Hackney

Practice name / vaccine	DTaP <sub>1</sub> IPHV Hib-12 month	DTaP <sub>1</sub> IPHV Hib-24 month	DTaP <sub>1</sub> IPV 5y	Men C 12 month	MMR1st5y	MMR24m	MMR2nd5y	PCV12m	PCV Booster24m	Hib Men C booster 24m	Hib Men C booster 5y
F84013	64.58	80.91	76.34	47.92	95.7	89.09	80.65	64.58	73.64	80	89.25
F84624	88.89	100	33.33	88.89	66.67	80	66.67	88.89	80	80	66.67
F84668	60	88.64	77.14	43.64	91.43	81.82	77.14	58.18	81.82	84.09	85.71
F84686	55.56	81.03	68	29.63	86	72.41	70	55.56	74.14	74.14	82

#### 4. Factors associated with immunisation coverage

Limited UK-based data is available to understand the reason for low coverage in this community, but research internationally suggests that uptake is influenced by several factors, which include:

- Birth order:** A study of over 100,000 Israeli children (including Jewish, ultra-orthodox Jewish and the Arab population) identified that a child's birth order was inversely related to vaccination status (of a voluntary varicella vaccine)<sup>9</sup>. This factor was identified to be of more significance than family size, country of birth and social and demographic parental features. A 2008 case-control study of a measles outbreak in a town close to Jerusalem child's rising birth order to be inversely associated with their registration at a well-baby clinic (where infant immunisations are provided)<sup>10</sup>. Of all measles cases, 82% of firstborn children were registered, compared to 44% for those fifth-born or above, compared to 100% and 96% respectively in controls. Birth order was also identified as a risk factor for "vaccine underutilization" in a study of 430 ultra-orthodox Jewish children in Israel<sup>11</sup>. This 2011 study used medical records and parental interviews to identify factors for sub-optimal immunisation coverage in children. In addition to birth order (having >6 siblings), maternal education, parental religious beliefs against vaccination, perceived risk of VPDs being low and a mistrust of the Ministry of Health were also identified. The authors concluded that increased health education and involvement of religious leaders could lead to a significant increase in immunisation coverage. Factors such as birth order are not unique for this community, but have been reported as being of importance in other countries and communities, each suggesting a relationship between

<sup>8</sup> Asnong C et al. *Lessons learned from a measles outbreak in Antwerp, Belgium 2007-2008*. Pediatric Infectious Disease Journal. 30 (4)

<sup>9</sup> Gavriellov-Yusim N, Battat E, Neumann L, Friger M, Balicer R. *Birth order and private voluntary immunization – a study of 110,902 children*. Vaccine. 2012; 30 (2)

<sup>10</sup> Stein-Zamir C et al. *Who are the children at risk? Lessons learned from measles outbreaks*. Epidemiology of Infection (2012), 140: 1578-1588.

<sup>11</sup> Khitam M, El-Hai R, Amit-aharon A, Nehama H, Gondia M, Davidovitch N, Goren S, Cohen D. *Risk factors of underutilization of childhood immunizations in ultraorthodox Jewish communities in Israel despite high access to health care services*. Vaccine. 2012; 30 (12)

parental ability to dedicate and prioritise the time needed to arrange and attend for childhood immunisations. Additionally, it is suggested that experience perhaps of a VPD in a younger child may reduce the priority a parent gives to immunisation for other children.<sup>12,13,14</sup>.

- **Health beliefs:** Studies have demonstrated differing opinions as to the importance of this factor within the communities. A 2008 UK based study concluded that participants linked low uptake to concerns over safety and danger relating to immunisations<sup>15</sup>. Within this small sample, uptake was not found to be due to practical difficulties or perceived insensitive cultural practices of health providers. As such, these findings differed from those of other studies in communities in the UK and overseas. For example, a previous questionnaire study in north-east London in 1994 of 67 orthodox Jewish parents identified that they considered immunization to be important and had positive attitudes to the value and safety of immunisations<sup>16</sup>. It is important to note that this study was conducted before the global MMR scare in 1998.
- **Access to immunisations:** Access to health or specific immunisation services is consistently highlighted in the literature and has been highlighted in the literature for many years<sup>16</sup>. Access is affected by the number of children within the family unit (reducing parental time) and services within schools. For example, a Belgium study noted that during a measles outbreak in 2011-12, an important factor for non-vaccination of children within orthodox Jewish communities was their attendance of private schools, which were not supported by a school health centre<sup>17</sup>. Additionally, in Belgium, these schools did not receive a MMR catch-up programme<sup>18</sup>.

## 5. Vaccine preventable diseases

Despite efforts, multiple outbreaks of vaccine-preventable diseases (e.g. measles and mumps) within Orthodox and Ultra-Orthodox Jewish communities across the world (Europe and the United States of America) have been, and continue to be reported<sup>19,20,21,22,23,24,25</sup>. A report of a measles outbreak in 2004 in Jerusalem resulted in 117 cases, including eight hospitalisations and one death in a child with

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<sup>12</sup> Miller L *et al.* Risk factors for delayed immunization against measles, mumps and rubella in Colorado two-year olds. *Pediatrics* (1994) 94 (2) 213-9

<sup>13</sup> Li J & Taylor B. *Childhood immunisation and family size.* *Health Trends* (1993) 25 (1): 16-9.

<sup>14</sup> Reading R *et al.* *Infant immunization and family size.* *Journal of Public Health.* 26 (4) 369-371

<sup>15</sup> Henderson L, Millet C, Thorogood N. *Perceptions of childhood immunization in a minority community: A qualitative study.* *Journal of the Royal Society of Medicine.* 2008; 101: 244-251

<sup>16</sup> Cunninghame C *et al.* *Immunization uptake and parental perceptions in a strictly orthodox Jewish community in north-east London.* *Journal of Public Health* (1994) 16 (3): 314-317.

<sup>17</sup> Sabbe M *et al.* *Measles epidemic in Belgium 2011-2012: Reasons for non-vaccination.* *Journal du Pédiatre Belge* (2013) Vol. 15 (1). Available at: <http://www.bvksbp.be/downloads/common/paper/20131501/2013150101.pdf>

<sup>18</sup> Lernout T, Kissling E, Hutse V, Schrijver KD, Top G. *An outbreak of measles in Orthodox Jewish communities in Antwerp, Belgium, 2007-2008: Different reasons for accumulation of susceptibles.* *Eurosurveillance.* 2009; 14 (2): 19087

<sup>19</sup> Stein-Zamir C, Abramson N, Shoob H and Zentner G. *An outbreak of measles in an ultra-Orthodox Jewish community in Jerusalem, Israel, 2007 – An in-depth report.* *Eurosurveillance* 13 (1-3) Jan – Mar 2008.

<sup>20</sup> Lernout T, Kissling E, Hutse V, Schrijver KD, Top G. *An outbreak of measles in Orthodox Jewish communities in Antwerp, Belgium, 2007-2008: Different reasons for accumulation of susceptibles.* *Eurosurveillance.* 2009; 14 (2): 19087

<sup>21</sup> Cohen BJ, McCann R, van der Bosch C, White J. *Outbreak of measles in an Orthodox Jewish community.* *Eurosurveillance.* 2004; 4 (3): 675. Available at: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=1675>

<sup>22</sup> Ashmore J, Addiman S, Cordery R, Maguire H. *Measles in North East and North Central London, England: a situation report.* *Eurosurveillance.* 2007; 12 (39): 3271 <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=3271>

<sup>23</sup> Muscat M. *Who gets measles in Europe?* *The Journal of Infectious Diseases.* 2011; 204: S353-S365

<sup>24</sup> Health Protection Agency. North East and North Central London Health Protection Unit, Annual Review 2011. Unpublished report.

<sup>25</sup> Bosch C *et al.* *Mumps outbreak confined to a religious community.* *Eurosurveillance.* 2000; 5 (5). Available at: [www.eurosurveillance.org/ViewArticle.aspx?ArticleId=15](http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=15)

an underlying lung disease<sup>26</sup>. The number of outbreaks, recurrence and their size indicate inadequate vaccination coverage, and their confinement, illustrates a significant degree of social segregation. These outbreaks cause a considerable burden of ill health to those whom acquire infections. Within the London community, the following clusters and outbreaks have been detected over the last 10 years:

- **Measles:** The most recent measles outbreak in 2012/13 resulted in **156** notifications of measles, predominately in children aged between 1 and 4 years. The outbreak caused over 10 children to be taken to hospital, of which more than 5 were admitted for at least one night.
- **Mumps:** **144** cases of mumps in the community notified between 1998 and 1999. Half of all cases not immunised. Links to Belgium and Israel and possible importation
- **Hepatitis A:** 2 cases in 2010 resulted in emergency immunisation of **900** community members

In the London community, infectious disease clusters and outbreaks have been observed, caused by infections other than vaccine-preventable diseases. These have included *Shigella sonnei*, meningococcal group B septicaemia and non-toxygenic *Corynebacterium diphtheriae* in London-based Orthodox Jewish communities<sup>27,28</sup>. None of these clusters or outbreaks has been found to have spread beyond the community which illustrates the tight social segregation of the community to the surrounding area.

## 6. Rationale

Vaccine-preventable diseases can cause both significant short and long-term effects to health and can result in socio-economic costs to patients, families and communities (particularly during an outbreak). They pose significant risk to vulnerable groups such as unvaccinated infants, pregnant women and those who are immune-suppressed. There is a paucity of evidence and current information regarding knowledge, attitudes and practices relating to immunisation, and the impact of service delivery upon uptake within London's Charedi Jewish community. This piece of local work using TIP seeks to address this, providing current and local information to inform commissioning and provision of immunisation programmes.

## 7. Stakeholder Meeting

A multi-agency meeting, hosted by PHE was held in London in April 2014 to inform local stakeholders of the TIP tool, offer examples of where this has been implemented within Europe and to discuss the usefulness and consider the practicalities of implementing this locally with the Charedi community. The meeting was attended by representatives from WHO Europe, NHS England, the London borough of Hackney Public Health Department, the Homerton University Hospital NHS Foundation Trust, a local Rabbi with a responsibility for health, and PHE (health protection and behavioural insights directorates).

It was agreed that this could be a very useful model were it implemented locally within the north London Charedi community, providing commissioners, providers and service users increased

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<sup>26</sup> Stein-Zamir *et al.* Measles outbreaks affecting children in Jewish ultra-orthodox communities in Jerusalem. *Epidemiology of Infection* (2007).

<sup>27</sup> Health Protection Agency. North East and North Central London Health Protection Unit, Annual Review 2011. Unpublished report.

<sup>28</sup> Efstratiou A, George R. Microbiology and epidemiology of diphtheria. *Reviews in Medical Microbiology*. 1996; 7 (1), 31-42

information relating to both the demand and supply-side barriers to childhood immunisation, and recommendations for providing an evidence-informed response.

## 8. Partners Meeting

A day-long local meeting was held in Stamford Hill, Hackney in July 2014, to introduce key health and community leads to the TIP model. The meeting was attended by representatives from 3 local children's centres serving the community, Homerton University Hospital NHS Foundation Trust providers, NHS England, a local Rabbi with responsibility for health, a general practice manager, the health policy lead for the Interlink Foundation and WHO Europe. The aims of the meeting were to:

- a) Provide participants with an overview of TIP
- b) Identify the strengths, weaknesses, opportunities and strengths relating to immunisations and the current programme for the local community.
- c) Seek participant's experience and knowledge to set the scene as this piece of work moves forward

### Partners Meeting: Discussion

The local community was noted to have 85 synagogues in the borough of Hackney alone, with the Charedi comprised of over 50 streams alone. Approximately 85% of the community in Stamford Hill, Hackney is thought to be Hassidic, 10% non-Hassidic and 5% Sefardi. As such, it was stressed that there are very different cultures and beliefs on a wide range of topics within the Charedi community as a whole. It was felt that this strong, distinct and growing community is very under-represented in the public sphere.

It was noted that given the community's population growth rate, this health issue is not going to go away without addressing the causes. To what degree are health services able to expand to match this growth? Approximately 25 babies are born into the community each week, resulting in a 4% net population growth year on year, with the community doubling in size every 15 years. Participants unanimously felt that access to services was the largest factor to sub-optimal immunisation coverage. It was felt that a few years ago health beliefs (fears or concerns about vaccine safety, efficacy and so on) would have been the strongest factor, but more recently there has been a shift with increasing acceptance, though perhaps still with some concern particularly regarding the MMR vaccine and fears regarding autism. It was noted that the Rabbinate has become willing to discuss childhood immunisations over the last couple of years, which is a significant shift and opportunity. Vaccine delay of infants was acknowledged to be a challenge to address, with some families preferring to hold all vaccines until their child reaches perhaps 2 years of age. Some mothers were noted to be anxious of their children receiving too many immunisations in one appointment, wanting to split the immunisations over two or more appointments. Homeopathy was also noted to be popular with a small proportion of families as an alternative to immunisation.

Communication was noted to be a challenge with many families without televisions or the internet at home. Messages regarding routine and travel immunisations are then challenged.

Participants felt that TIP would be useful and applicable for the community given the context of recurrent outbreaks and poor immunisation coverage. As such, the outcomes of the meeting are given below, with the SWOT analysis illustrated in Table 2 and discussion outcomes about local implementation of TIP and associated next steps below.



## Partners Meeting: SWOT Analysis

**Table 2.** SWOT analysis of the local immunisation programme (conducted by participants at the Partners Meeting, July 2014)

<b>Strengths of the local immunisation programme</b>	<b>Weakness of the local immunisation programme</b>
<ol style="list-style-type: none"> <li>1. Immunisation clinics in three children’s centres: Convenient times and family-friendly facilities, resulting in a good patient experience.               <ol style="list-style-type: none"> <li>a) Friday afternoon summer clinics</li> <li>b) Sunday monthly clinics (Lubavitch)</li> <li>c) Wednesday weekly clinic (Norwood)</li> </ol> </li> <li>2. Immuniser from the community and other staff who have a positive attitude towards the community.</li> <li>3. Free immunisations</li> <li>4. Universally available</li> <li>5. Willingness of the community and professional stakeholders to work collaboratively in identifying and overcoming immunisation barriers.</li> <li>6. Significant enthusiasm within the community to improve immunisation uptake.</li> <li>7. Contacting families who don’t, or delay immunisations and discussing concerns with them appears to change some beliefs and behaviours. It was noted that this was only successful with sufficient time and cultural understanding.</li> </ol>	<ol style="list-style-type: none"> <li>1. Current facilities at GP practices reported to give poor patient experience:               <ol style="list-style-type: none"> <li>a. Long waiting times</li> <li>b. Poor family friendly facilities (e.g. no toys and not enough space for buggies)</li> </ol> </li> <li>2. Not enough immunisers to meet potential demand</li> <li>3. Reported difficulties in getting appointments for those who want to vaccinate their child</li> <li>4. Traditional communication methods unsuitable e.g. internet, text messages, press</li> <li>5. Insufficient cultural awareness training that can be applied to immunisations</li> <li>6. Inadequate resource allocation to recognise the unique characteristics of the community e.g. larger families, younger population, cultural and religious practices</li> <li>7. No or little access to school aged immunisations from the school nursing service</li> <li>8. Lack of any provision to encourage fathers to attend vaccination clinics</li> <li>9. Some members felt the community felt “attacked” by professionals on the issue of immunisation.</li> <li>10. Too many presumptions as to what the community want and don’t want regarding health services.</li> <li>11. Innovative solutions often not sustained</li> </ol>
<b>Opportunities of the local immunisation programme</b>	<b>Threats to the local immunisation programme</b>
<ol style="list-style-type: none"> <li>1. Extension of children centre immunisation provision e.g. after school 4-6 Monday-Wednesday</li> <li>2. Summer schemes</li> <li>3. Community specific communications e.g. use of community pharmacists (who are administering vitamin drops, etc. already to families)</li> </ol>	<ol style="list-style-type: none"> <li>1. Sustainability/funding for expansion of targeted services</li> <li>2. Vaccine myths are still prevalent in the community e.g. MMR</li> <li>3. Very close knit community making it difficult to spread positive messages about immunisations</li> <li>4. Closed community</li> </ol>

<p>4. Service development e.g. more father friendly clinics</p> <p>5. To use local advertising through free weekly newssheets</p> <p>6. To work in school with young women who will be future mums</p> <p>7. Consider creating “community champions” for immunisations.</p>	<p>5. Resource constraints to expand and run bespoke clinics</p> <p>6. Potential change of political climate</p>
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### Partners Meeting: Questions

- **Data:**
  - Can we obtain COVER trends (at practice level) in the community over 10+ years?
  - What is the prevalence of VPDs in the community over the last 10 years?
- **Service evaluation:**
  - How effective are the community clinics?
    - How many immunisations are given
    - How many staff are employed
    - What are the demographics of families attending
    - Which vaccines are commonly administered
    - What can GP services learn from these clinics which appear popular?
    - What proportion of children are currently receiving their immunisations in community clinics (as opposed to GP practices)?
  - Have local practices evaluated their immunisation services? Could an agreed audit and survey be implemented by all?
  - Is there a need for cultural training of local health care providers?
- **Communication and knowledge**
  - Community knowledge:
    - Do people know what vaccines they are to have and are entitled to (e.g. travel and pregnancy vaccines)?
    - Have there been any adverse events associated with immunisation in the community (check surveillance)? If not, could this be highlighted / promoted?
    - Could we use opportunities to promote immunisations? E.g. schools, girls’ pre-marriage courses (16 and 17 years of age)
- **Segmentation:**
  - What can we learn about those families delaying childhood immunisations?
  - What can we learn about those families refusing childhood immunisations?
  - Is there a need for cultural training of local health care providers?

## B. The purpose of this study

### 1. Study Aim

To gain an in-depth understanding of the reasons for vaccine hesitancy amongst parents who are part of the Charedi community in Hackney and Haringey, with the aim of tailoring childhood immunisation services accordingly in order to improve uptake rates.

### 2. Study Objectives

1. To explore the reasons why Charedi parents delay or refuse vaccination for their child;
2. To learn about Charedi parents' recent experience with the childhood immunisation programme;
3. To identify what information sources are viewed as trustworthy by Charedi parents;
4. To explore Charedi parents' decision-making processes concerning childhood immunisation;
5. To establish the barriers and facilitators that influence uptake of childhood immunisation in the Charedi community;
6. To recommend how the childhood immunisation programme could be better tailored towards the needs of the Charedi community.

## C. Study design

### 1. Summary

The purpose of this study is to gain an in-depth understanding of parental views of vaccines and immunisation services within the Charedi community in Hackney and Haringey, with the aim of informing the implementation of this programme. To achieve this we will interview parents who are either not up to date, or unsure if they are up to date, with their children's immunisations. We will also interview key informants who could have insights on this topic.

### 2. Study population, recruitment and sampling

The study population consists of parents with at least 1 child under 6yrs of age, who have completed a questionnaire about immunising their child(ren) in the Charedi community in Hackney and Haringey, and agreed to be contacted to take part in a research interview. The study population also consists of key informants from these areas, who can provide insights on the topic, such as local GPs, Rabbis, nurses, other primary care staff, GP receptionists and children's centre receptionists.

#### *a) Parent recruitment procedures*

A cross-sectional questionnaire survey about childhood immunisation in the Charedi community in Hackney and Haringey is being conducted by Public Health England (see Appendix 1 for the questionnaire). The questionnaire has been piloted in a children's centre. Of the 34 questionnaires completed, 7 parents agreed to be contacted to take part in an interview.

The questionnaire will be distributed over a 3 week period, in May – June 2015, in 3 children’s centres and 7 GP practices in the Charedi community in Hackney and Haringey in London. This has a targeted cohort of approximately 6800 parents. Parents within the Charedi community in Hackney and Haringey who have at least 1 child under 6 years of age will be asked to complete the questionnaire. Of these participants, those that ticked the box in the questionnaire “Yes, I am willing to be contacted about taking part in interviews to help improve immunisation services within the Charedi community” will be contacted.

Parents will be contacted by phone or email by a study investigator depending on their preferred choice of contact. If by email a study investigator will send a summary of the study to see if they would be interested in participating. If yes, a study investigator will contact them by phone. In this phone call the investigator will go through the study information sheet (see Appendix 2) in more detail giving parents the opportunity to ask any questions. The investigator will then ask the parent if they are willing to take part in a face-to-face interview and if they reply affirmatively an interview date and appointment will be scheduled.

Interviews will take place in parents’ homes or in a place of their preference which is conducive to a confidential exchange. Interviews will involve one of the investigators and one or both parents or where appropriate legal guardian(s). Before the interview starts the investigator will go through the study information sheet with the potential interviewees to ensure that they have understood the purpose of the research, are aware of how we will use the information that they will share with us and how we will maintain their confidentiality (see the section on ethical considerations). They will then be asked to complete a consent form if they are happy to proceed with the interview (see Appendix 3). Interview participants will be given a £20 Post Office multi-store gift card to thank them for their time.

#### *b) Key informant recruitment procedures*

Through study contacts, key informants will be contacted by email with a short summary of the study to see if they would be interested in being interviewed as a key informant. Those that respond expressing interest in the study will be emailed a study information sheet and consent form (see Appendices 3 and 4). If still interested they will be contacted by phone by a study investigator to give them the opportunity to ask any questions. The investigator will then ask the key informant if they are willing to take part in a face-to-face interview and if they reply affirmatively an interview date and appointment will be scheduled.

Interviews will take place in the key informant’s place of their preference which is conducive to a confidential exchange. Before the interview starts the investigator will go through the study information sheet with the potential interviewee to ensure that they have understood the purpose of the research, are aware of how we will use the information that they will share with us and how we will maintain their confidentiality (see the section on ethical considerations). They will then be asked to complete a consent form (see Appendix 3) if they are happy to proceed with the interview. Interview participants will be given a £20 Post Office multi-store gift card to thank them for their time.

### c) Sampling

We will apply a purposive sampling approach to ensure that our sample reflects wide ranging socio-demographic characteristics and a good representation of the community. We will review our sample characteristics during the study recruitment in order to identify if we are missing out a particular subgroup of parents, for example parents from certain districts, or if our sample is biased towards attendance of a particular synagogue/or related group of synagogues. We will also seek to conduct interviews with fathers as well as mothers either alone or as a couple. This will allow us to observe decision-making dynamics between parents. We will approach key informants from the spectrum (local GPs, Rabbis, nurses, other primary care staff and receptionists).

For the key informants, we will supplement our purposive sampling with snowball sampling, asking key informants if they have contacts that could provide insights and might be interested in participating in the study.

We anticipate to reach theoretical saturation (i.e. the point at which no new concepts emerge from the review of successive data collection) for our parent interviews after conducting 20-30 interviews. We will continue to contact parents who completed the questionnaire, stating they agreed to be contacted, until we reach theoretical saturation. We aim to conduct 10-20 key informant interviews.

### 3. Data collection

Study data will be collected from parents by the means of semi-structured interviews. This approach allows us to cover predefined topics and provide the necessary flexibility for the interview to be shaped by interviewees' interests, their roles and experiences. We have developed an interview topic guide for parents (see Appendix 5), which we will use to capture socio-demographic information and cover six main topics: Parents' recent experience with the childhood immunisation programme, Reasons parents delay or refuse vaccination for their child, barriers or promoters of vaccination, risk-benefit considerations, information sources viewed as trustworthy, and parental decision-making processes concerning childhood immunisation. The interview guide has been developed to encourage the participants to talk and to give their views and opinions, and not with the emphasis of convincing the parents that they need to immunise their child.

We have developed an interview topic guide for key informants (see Appendix 6). In this we cover involvement, experience and understanding of children's immunisation, parental decision-making, and parent's reasons for delaying vaccination, risk-benefit considerations, and barriers or promoters of vaccination.

With the permission of participants we will record these interviews verbatim with the use of a digital recorder. In cases where interviewees would prefer not to be recorded, we will take field notes during and after the interview. Even when we can record our interactions, we will keep field notes which will allow us to record pertinent issues that come up in the interview and may need to be revisited, and discussed with other interviewees.

The parental interviews will take place in parents'/legal guardians' homes or a place of their choosing, which is conducive to a confidential exchange. In instances where English is not interviewees first

language they will be asked if they would find it helpful to have somebody interpret for them during the interview. The key informant interviews will take place in a location of their choosing, which is conducive to a confidential exchange.

#### 4. Data analysis

The data analysis will be mainly thematic (Boyatzis 1998), although techniques outlined by Strauss and Corbin (1998), which are common to grounded theory, will also be applied i.e. open coding and the constant comparative method. Data analysis will proceed in tandem with data collection and the investigators will meet regularly to discuss emerging findings, fine tune interview questions accordingly, define codes and higher level themes and categories, and then map and finalise a coding framework. Interview recordings will be transcribed anonymously externally and the transcriptions will be downloaded into a qualitative data analysis software programme (NVivo). This programme facilitates the display, coding and management of qualitative data. Electronic summaries of anonymised field notes will also be downloaded into our NVivo project folder in order to provide relevant contextual detail. Two of the investigators (TC and PP) will both code the first 5 transcripts from parents and key informants individually and develop a coding framework, in order to be able to compare their findings, enhance consistency and start to develop a coding framework. At this point they will meet to discuss the emerging findings and produce a comprehensive and coherent coding framework. They will then use this framework to code all transcripts. When this is complete the investigators (TC, HL, PP) will meet again to summarise their preliminary findings, which they will present to the research collaborators and members of the Health Protection Research Unit at LSHTM. Feedback received during these sessions will allow them to critique their analytical approach and findings and assist in compiling a detailed final report on the study findings.

#### D. Study Management

This study is conducted as part of the research programme of a health protection research unit (HPRU) in immunisation which is based at LSHTM in partnership with Public Health England. The study investigators report to the steering committee of the HPRU on a regular basis. Public and key stakeholder representatives are part of this steering committee.

The study will be carried out in close collaboration with Public Health England staff, who are associated with the HPRU.

#### E. Funding and insurance

This study is funded by the National Institute of Health Research (NIHR) as part of the establishment of health protection research unit (HPRU) in immunisation at LSHTM in partnership with Public Health England. LSHTM is the sponsor of this study and will be responsible for sponsor related duties including monitoring and insurance.

## F. Ethical considerations

This study will be reviewed by the LSHTM Observational Research Ethics Committee and the committee's approval will be obtained prior to commencement of any research activities. The study investigators will obtain informed consent from participants and will ensure that their anonymity is maintained. Where necessary (limited understanding of English) an interpreter will support the informed consent process and help translate during the interview.

PHE have received a favourable ethical opinion for the Questionnaire part of the study by NRES Committee North East – Newcastle & North Tyneside 2 (REC reference 15/NE/0021, IRAS project ID 140871, dated 14 January 2015). PHE also have local NHS ethics approval (NHSE Research Governance Assurance) from NOCLOR for the Questionnaire part of the study.

PHE will send an amendment to the IRAS form, adding in the additional element relating to the in-depth interviews.

Participants will be informed that their participation is voluntary and that they are allowed to refuse to answer any question or end the interview at any time. The interview guide for parents/guardians has been developed to encourage the participants to talk and to give their views and opinions, and not with the emphasis of convincing them that they need to immunise their child.

The interviews will be audio-recorded, with the participants' consent and transcribed. Recordings and transcripts of interviews will be stored anonymously using a numerical identifier on password protected computers. Only the investigators will have access to the files that link a numerical identifier to a participant's name. The research sites will be allocated a numerical identifier. Anonymised quotations from participant interviews may be used in study reports or published articles. Confidentiality will be maintained by referring to quotations using the code assigned to the area and the participant's role only (e.g. Area 1, Parent 2) and extra care will be taken to ensure that participants or organisations cannot be identified through contextual information.

## G. Dissemination and publication plans

The investigators and collaborators will be involved in reviewing drafts of the manuscripts, abstracts, press releases and any other publications arising from the study. Authors will acknowledge that the study was funded by the NIHR. Authorship will be determined in accordance with the ICMJE guidelines and other contributors will be acknowledged. We aim to publish this work in an open access journal to ensure that it is widely available.

An interim and a final report will be provided to NIHR, PHE and organisations who were involved in commissioning and implementing the childhood vaccination programme. Presentations and informal reports and media briefings will also be provided, if required. We also intend to take part in, and present to, networking events and more focused workshops that are organised for organisations and staff involved in immunisation activities.

## H. Timeline

May 2015	Submit ethics application to the LSHTM Observational Research Ethics Committee
Nov 2015	Submit amendment to the LSHTM Observational Research Ethics Committee
Dec 2015-Jun 2016	Recruit participants Conduct interviews Interviews transcribed externally Code interviews and analyse themes
April 2016	Present preliminary findings to collaborators at workshop
July 2016	Complete NHS Commissioning report
August 2016	Submit research publication Complete and send summary report of findings to study participants

## I. Investigators & Collaborators

The investigators have created the study information sheets, interview topic guides, and consent form. The investigators will conduct the interviews, carry out data collection, analysis and write up. PHE created the questionnaire and will collect the completed questionnaires with the help of collaborators. PHE will analyse the questionnaire data and share the information of the parents who agree to be contacted for interview. PHE partners will have access to the anonymised data.

### Principal Investigators:

Dr Pauline Paterson, The Vaccine Confidence Project, Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, LSHTM

Dr Paterson co-leads the Vaccine Confidence Project. Dr Paterson has been researching concerns around vaccines in the Vaccine Confidence Project since 2010, has experience of conducting research interviews in England, and of qualitative data analysis related to vaccine uptake.

Vanessa Rew, Public Health England, North East & North Central London, HPT

Vanessa Rew is a nurse consultant working in the local Health Protection Team with Public Health England where her work focusses on communicable disease surveillance, response and immunisation advice to local organisations. She has experience in conducting qualitative research in the UK (detained adult migrant group) and in India.

Parental views of the childhood immunisation programme in the London Charedi orthodox Jewish Community Protocol, v4, dated 21<sup>st</sup> June 2016. LSHTM Ethics Ref: 10061



#### Co-Investigators:

Dr Heidi Larson, The Vaccine Confidence Project, Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, LSHTM

Dr Heidi Larson previously headed Global Communication for Immunization at UNICEF and Chaired the Advocacy Task Force for the Global Alliance for Vaccines and Immunization (GAVI), and is a member of the WHO SAGE working group dealing with vaccine hesitancy. Dr Larson has qualitative research experience and has conducted extensive research with Pakistani community in South Africa, and has also addressed similar concerns in the polio programme.

Dr Tracey Chantler, Department of Global Health and Development, Faculty of Public Health and Policy, LSHTM

Tracey Chantler has been involved in research relating to vaccines and immunisation for 15 years. She also has experience of training health workers in vaccination and coordinating immunisation programmes in Haiti. Her research in this field spans paediatric clinical vaccine trials, qualitative and mixed methods research in the UK related to trial participation and vaccine uptake, and long-term ethnographic fieldwork related to community engagement, vaccine trials and ethics in western Kenya.

#### Collaborators:

##### Public Health England:

Louise Letley, Senior Research Coordinator, Immunisation Implementation & Planning, Immunisation Operations, Immunisation, Hepatitis & Blood Safety Department

Dr Jo Yarwood, National Immunisation Programme Manager and Head of Implementation and Planning, Immunisation, Hepatitis & Blood Safety Department

##### NHS England:

Rehana Ahmed, Immunisation Manager, NHSE London

J.Appendix 1: PHE Questionnaire



Any questions about this questionnaire?  
Please call the north east and north central London Health Protection  
Team, PHE: 020 3837 7084

**Please tell us about children’s immunisations in your community**

We are exploring factors that encourage or prevent you from immunising your children. If you are a parent or guardian of a child aged less than 6 years, we would really welcome your views. All responses will be reviewed and compiled in a report for the community and those who commission and provide the service. We can send the report to you if you add your details to the final page.

If you do not wish to complete this questionnaire, please just say so when you are approached with this form.

Responses are completely anonymous, unless you choose to provide your details on the final page. If you do this, your contact details will be stored confidentially. All answers will be stored in our secure system.

1. Are you the parent or a guardian of one or more children aged under six years?	<input type="checkbox"/> <sub>1</sub> Yes	<input type="checkbox"/> <sub>2</sub> No			
<i>If 'no', thank you for your time but you don't need to complete the survey as we are only looking for the views of parents or guardians of children under 6 years of age.</i>					
2. What age are you?	<input type="checkbox"/> <sub>1</sub> 16-19 years	<input type="checkbox"/> <sub>2</sub> 20-24 years	<input type="checkbox"/> <sub>3</sub> 25-29 years		
	<input type="checkbox"/> <sub>4</sub> 30-34 years	<input type="checkbox"/> <sub>5</sub> 35-39 years	<input type="checkbox"/> <sub>6</sub> 40 years +		
3. What is your gender?	<input type="checkbox"/> <sub>1</sub> Female	<input type="checkbox"/> <sub>2</sub> Male			
4. How many children aged under 6 years live with you?	..... Please write in number				
5. Are all these children up to date with their immunisations?	<input type="checkbox"/> <sub>1</sub> Yes Please go to Q6	<input type="checkbox"/> <sub>2</sub> No Please go to Q7	<input type="checkbox"/> <sub>3</sub> Not sure		
6. If, yes, please give reason(s) for choosing to immunise? <i>Please tick all that apply</i>	<input type="checkbox"/> <sub>1</sub> I want to protect my child from illness	<input type="checkbox"/> <sub>2</sub> I know a child who was ill from a vaccine preventable disease eg measles			
	<input type="checkbox"/> <sub>3</sub> I believe vaccination is important to prevent spread of disease in the community	<input type="checkbox"/> <sub>4</sub> Health Professional recommendation			
	<input type="checkbox"/> <sub>5</sub> Friend or family recommendation	<input type="checkbox"/> <sub>6</sub> Community member recommendation			
	<input type="checkbox"/> <sub>7</sub> The facilities at the immunisation clinic were child friendly	<input type="checkbox"/> <sub>8</sub> It was easy to get an appointment			
	<input type="checkbox"/> <sub>9</sub> Other (please provide details below)				
Please provide any additional suggestions/comments	Please go to Q8				
7. If 'No' please give the reason(s) for the child(ren) not being up to date with their immunisations?					
8. How helpful do you think the following suggestions would be in improving immunisation services for the Charedi community?					
	Not helpful	Slightly helpful	Moderately helpful	Quite Helpful	Very Helpful
a) More vaccination sessions at children's centres	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>

b) More vaccination sessions in community locations <i>E.g. community halls, shopping centres etc.</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
c) Sunday appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
d) More after school appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
e) More child-friendly facilities in General practices/Health Centres <i>Eg; access or secure parking for buggies, play area for children, baby changing facilities etc</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
f) Shorter waiting time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
g) More fixed appointments rather than 'drop-in' clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
h) More drop-in clinics rather than fixed appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
i) Home visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
j) Text reminders for appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Please provide any additional suggestions/comments							
<b>9. Where would you usually go for advice on vaccination?</b>							
General Practice / Doctors surgery <input type="checkbox"/>	Children's centre <input type="checkbox"/>	Friends/family <input type="checkbox"/>	Health visitors <input type="checkbox"/>	Community newsletters <input type="checkbox"/>	Other <i>Please specify</i> <input type="checkbox"/> .....		
<b>10. How satisfied were you with the information provided?</b>							
Completely dissatisfied <input type="checkbox"/>	Slightly dissatisfied <input type="checkbox"/>	Neither satisfied nor dissatisfied <input type="checkbox"/>	Slightly satisfied <input type="checkbox"/>	Completely satisfied <input type="checkbox"/>			
<b>11. How helpful do you think the following suggestions would be in improving the immunisation information provided to the Charedi community?</b>							
			Not helpful	Slightly helpful	Moderately helpful	Quite Helpful	Very Help ful
a) More information on benefits and risks of vaccination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Community 'Champions' <i>ie. People within the Charedi community whom you could approach for information and advice</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) More information on immunisation provided in community newsletters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Community immunisation advice line	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Charedi nurses providing immunisation service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please provide any additional suggestions/comments							

**Thank you for completing this questionnaire**

Yes, I would like to receive a copy of the final report from this study

*We will be running a series of interviews to discuss the issues that arise from the questionnaire responses. If you are interested in further helping to shape immunisation services in your community and would like to be included in these discussions please indicate below:*

Yes, I am willing to be contacted about taking part in interviews to help improve immunisation services within the Charedi community

If you have answered yes to either of the points above, then please provide contact details below:

#### Contact details

<b>Name:</b>	
<b>Phone:</b>	
<b>Mobile:</b>	
<b>Email:</b>	
<b>Instructions</b>	<i>E.g. preferred method of contact or best day or time to call</i>

**Anonymous:** If you wish your questionnaire responses to remain anonymous, remove this final page and return this sheet *separately* to the receptionist (if given to you in a GP surgery or Children's Centre) or by post to:

North East London Health Protection Team  
Ground Floor, South Wing  
Fleetbank House  
2-6 Salisbury House  
London  
EC4Y 8JX

Alternatively, you can contact us on:

E-mail: [necl.team@phe.gov.uk](mailto:necl.team@phe.gov.uk)

Telephone: 020 3837 7084

Version 3.0

## K. Appendix 2: Study information sheet for parents

### Study Information Sheet - Parents

#### Children's immunisations in the London Charedi Jewish Community

*You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to talk to others about the study, if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.*

#### 1. What is the purpose of the study?

The purpose of this study is to gain an in-depth understanding of parental views of vaccines and immunisation services within the Charedi community in Hackney and Haringey, with the aim of informing the implementation of this programme.

#### 2. Why have I been chosen?

You have 1 child (or more) who is under 6 years of age and you live within the Charedi community in Hackney and Haringey. You kindly completed the questionnaire about immunising children in the Charedi community, stating that you either delayed or were unsure if you had delayed vaccination for your child. You also said that you were willing to be contacted about taking part in interviews about immunisations services within the Charedi community. We would like to learn more about your views about childhood immunisation and about what influenced your decision. In total we expect to interview 20-30 parents from Hackney and Haringey. We will also interview local GPs, Rabbis, nurses, other primary care staff, GP receptionists and children's centre receptionists.

#### 3. Do I have to take part?

It is up to you to decide if you would like to join the study or not and take part in an interview, and the information provided in this sheet should help you decide. A study investigator will contact you in the next few weeks to answer any questions and see if you are interested in taking part in our study. If you agree to take part, we will arrange a time to meet at your home or a place of your choosing. Before you talk to us about your experience of the childhood immunisation programme you will be asked to sign a consent form. You are free to withdraw at any time, even during the interview, without giving a reason. Deciding not to take part in this study will not affect your relationship with your child's GP or your or your child's access to health care.

#### 4. What will happen if I agree to take part?

If you agree to take part in this study a researcher from the London School of Hygiene & Tropical Medicine will visit you in your home, or a place of your choice, to talk to you about your child's immunisations. This will include talking about your views on childhood immunisation, and the reasons you might have delayed vaccination. Your views are very

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important, and what you tell us will help inform the way the childhood immunisation programme is conducted in future in the Charedi community.

The interview will last about an hour and can be with one or both parents, or someone who is recognised as a legal guardian for the child who was offered a vaccine. The interviewer will take notes and with your permission the interview will be audiotaped. The audio-recordings from the interview will be transcribed into text, and anonymised so that the people taking part in the interview cannot be identified. We will store the interview data securely in line with Research Ethics Committee guidelines and only members of the research team will have access to this. We may use quotes from the interviews in reports and academic publications but these will be anonymous.

#### **5. Expenses and payments**

You should not incur any expenses from taking part in this study since the interviews will take place in your home or a place which is convenient for you. To compensate you for your time and engagement we will provide you with a £20 Post Office multi-store gift card, which can be used at a wide range of shops.

#### **6. What are the possible disadvantages and risks of taking part?**

You may feel uncomfortable about talking about your decision to delay to have your child vaccinated. The researchers, who will be interviewing you, do not work for the NHS or any of the organisations who were involved in organising the children's immunisation programme. They will respect your confidentiality and any information you share with them will be anonymised, which means that your names will not appear in any research documents.

#### **7. What are the possible benefits of taking part?**

Taking part in the study is unlikely to benefit you or your child directly, however the information you share with us will help inform the way that future childhood immunisation programmes are organised in this Charedi community.

#### **8. Will my taking part in the study be kept confidential?**

Yes. All information collected about you during the course of the research will be kept strictly confidential. Your name or your child's name will not appear in any reports or publications and we will not tell anyone about your participation in this study.

#### **9. What will happen if I do not want to carry on with the study?**

You are free to withdraw from this study at any stage, even during the interview. If you want to withdraw from the study we will ask you whether you are happy for us to use any of the anonymous information you shared with us during the interview, or whether you would like us to destroy the recording and the transcript of your interview.

Children's immunisations in the London Charedi Jewish Community

Study Information Sheet – Parents, version 4, dated 16<sup>th</sup> December 2015. LSHTM Ethics Ref: 10061

## **10. What will happen to the results of the research study?**

The results of this study will be written up in a report which will be shared with people who are responsible for running and planning the childhood immunisation programme. This includes staff who work for NHS England and related service providers, staff who work for Public Health England, and researchers based at the London School of Hygiene & Tropical Medicine. The report will also be sent to the National Institute of Health Research who is funding this study. We will also publish findings from our research in academic journals and comment on these on the London School of Hygiene & Tropical Medicine website. We may be asked to comment on our research and findings by representatives of the media. You will not be identified in any report, publication or media communications and we will send you a summary of our research findings and a copy of the main published paper.

## **11. Who is organising and funding the research?**

This research is being funded by the National Institute of Health Research and conducted by the London School of Hygiene & Tropical Medicine (LSHTM) in collaboration with Public Health England (PHE). The principal investigators are Dr Pauline Paterson (LSHTM) and Vanessa Rew (PHE).

## **12. Who has reviewed the study?**

This study was given a favourable ethical opinion by the London School of Hygiene & Tropical Medicine Observational Research Ethics Committee and the Health Research Authority, Research Ethics Service, Newcastle and North Tyneside 2 Research Ethics Committee.

## **13. Contact Details**

If you would like to find out more or have any questions about this study please contact Pauline Paterson or Tracey Chantler on Tel: 0207 927 2830. If you phone and there is no answer, please do leave a message on the answerphone, and we will get back to you as soon as possible. If you decide to take part in the study and subsequently have any concerns relating to your participation that you would like to discuss with somebody independent you can contact [ethics@lshtm.ac.uk](mailto:ethics@lshtm.ac.uk).

**Thank you for considering our study and taking the time to read this study information sheet.**

Children's immunisations in the London Charedi Jewish Community

Study Information Sheet – Parents, version 4, dated 16<sup>th</sup> December 2015. LSHTM Ethics Ref: 10061

L. Appendix 3: Consent form



**INFORMED CONSENT FORM**

**Study title:**

**Children’s immunisations in the London Charedi Jewish Community:  
An in-depth qualitative analysis**

*Please  
initial box*

1. I confirm that I have read and understand the participant information sheet dated ..... (version .....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I agree to my interview being recorded and transcribed.	
4. I agree to be quoted anonymously in publications or reports released on the study.	
5. I agree to take part in the above study.	

Participant’s Name

Date

Signature

Researcher’s Name

Date

Signature

**LSHTM Contacts:**

Pauline Paterson & Tracey Chantler, The Vaccine Confidence Project, Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, LSHTM, Keppel Street, London, WC1E 7HT. Tel: 0207 927 2830 Email: [pauline.paterson@lshtm.ac.uk](mailto:pauline.paterson@lshtm.ac.uk)

Principal Investigators: Dr Pauline Paterson (LSHTM) and Vanessa Rew (PHE)

This study has been approved by the London School of Hygiene & Tropical Medicine’s Research Ethics Committee and is funded by the National Institute for Health Research

1 copy for participant; 1 copy for Principal Investigator

Children’s immunisations in the London Charedi Jewish Community: An in-depth qualitative analysis  
Consent form version 1, dated 28<sup>th</sup> May 2015. LSHTM Ethics Ref: 10061



## M. Appendix 4: Study information sheet for key informants

### Study Information Sheet - Key Informants

#### Children's immunisations in the London Charedi Jewish Community

*You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to talk to others about the study, if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.*

#### 1. What is the purpose of the study?

The purpose of this study is to gain an in-depth understanding of parental views of vaccines and immunisation services within the Charedi community in Hackney and Haringey, with the aim of informing the implementation of this programme.

#### 2. Why have I been chosen?

You have been approached about this study because you either live or work in the Charedi community in Hackney or Haringey and are either involved in the children's immunisation programme or have been in contact with parents about it. You were nominated, and your contact details have been sought by Vanessa Rew, Nurse Consultant in the local Health Protection Team of Public Health England.

We would like to talk to you about your views about the children's immunisation programme and any related issues. Your views are very important because you represent faith groups, relevant societies, and involved public health teams in your area. We want to talk to a wide range of people and also plan to interview 20-30 parents from Hackney and Haringey, who have 1 child (or more) who is under 6 years of age and have either delayed or are unsure if they delayed vaccination for their child.

#### 3. Do I have to take part?

It is up to you to decide if you would like to join the study or not and take part in an interview, and the information provided in this information sheet should help you decide. If you agree to take part, we will arrange a time to meet at a place of your choosing. Before you talk to us about your experience of the children's immunisation programme you will be asked to sign a consent form. You are free to withdraw at any time, even during the interview, without giving a reason.

#### 4. What will happen if I agree to take part?

If you agree to take part in this study a researcher from the London School of Hygiene & Tropical Medicine will visit you at a place of your choice. They will talk to you about your involvement, experience and understanding of the children's immunisation programme in the Charedi community, and any interactions you have had with parents of children

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Study Information Sheet – Key Informants, version 3, dated 16<sup>th</sup> December 2015. LSHTM Ethics Ref: 10061

who delayed vaccination, and any concerns which were voiced. While we do want you to draw on and talk to us about your own real experiences it is important that you try not to name any specific people, or give us information that could render anyone identifiable. If you do that data will not be included in the analysis. Your views are very important, and what you tell us will help inform the way the children's immunisation programme is conducted in future in Charedi communities in England.

The interview will last about an hour and will be audiotaped with your permission. The audio-recordings from the interview will be transcribed into text, and anonymised so that the people taking part in the interview cannot be identified. We will store the interview data securely in line with Research Ethics Committee guidelines and only members of the research team will have access to this. We may use quotes from the interviews in reports and academic publications but these will be anonymous.

#### **5. Expenses and payments**

You should not incur any travel expenses from taking part in this study since we will try to ensure that the interviews take place in a location which is convenient for you. To compensate you for your time and engagement we will provide you with a £20 Post Office multi-store gift card, which can be used at a wide range of shops.

#### **6. What are the possible disadvantages and risks of taking part?**

You may feel uncomfortable about talking about your views about the children's immunisation programme. The researchers, who will be interviewing you, do not work for the NHS or any of the organisations who were involved in organising the children's immunisation programme. They will respect your confidentiality and any information you share with them will be anonymised, which means that your name will not appear in any research documents.

#### **7. What are the possible benefits of taking part?**

Taking part in the study is unlikely to benefit you directly, however the information you share with us will help inform the way that future children immunisation programmes are organised in this Charedi community.

#### **8. Will my taking part in the study be kept confidential?**

Yes. All information collected about you during the course of the research will be kept strictly confidential. Your name will not appear in any reports or publications and we will not tell anyone about your participation in this study.

#### **9. What will happen if I do not want to carry on with the study?**

You are free to withdraw from this study at any stage, even during the interview. If you want to withdraw from the study we will ask you whether you are happy for us to use

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any of the anonymous information you shared with us during the interviews, or whether you would like us to destroy the recording and the transcript of your interview.

#### **10. What will happen to the results of the research study?**

The results of this study will be written up in a report which will be shared with people who are responsible for running and planning the childhood immunisation programme. This includes staff who work for NHS England and related service providers, staff who work for Public Health England, and researchers based at the London School of Hygiene & Tropical Medicine. The report will also be sent to the National Institute of Health Research who is funding this study.

We will also publish findings from our research in academic journals and comment on these on the London School of Hygiene & Tropical Medicine website. We may be asked to comment on our research and findings by representatives of the media. You will not be identified in any report, publication or media communications and we will send you a summary of our research findings and a copy of the main published paper.

#### **11. Who is organising and funding the research?**

This research is being funded by the National Institute of Health Research and conducted by the London School of Hygiene & Tropical Medicine (LSHTM) in partnership with Public Health England (PHE). The principal investigators are Dr Pauline Paterson (LSHTM) and Vanessa Rew (PHE).

#### **12. Who has reviewed the study?**

This study was given a favourable ethical opinion by the London School of Hygiene & Tropical Medicine Observational Research Ethics Committee and the Health Research Authority, Research Ethics Service, Newcastle and North Tyneside 2 Research Ethics Committee.

#### **13. Contact Details**

If you would like to find out more or have any questions about this study please contact Pauline Paterson or Tracey Chantler on Tel: 0207 927 2830 or send an email to [pauline.paterson@lshtm.ac.uk](mailto:pauline.paterson@lshtm.ac.uk). If you phone and there is no answer, please do leave a message on the answerphone, and we will get back to you as soon as possible.

If you decide to take part in the study and subsequently have any concerns relating to your participation that you would like to discuss with somebody independent you can contact [ethics@lshtm.ac.uk](mailto:ethics@lshtm.ac.uk).

**Thank you for considering our study and taking the time to read this study information sheet.**

Children's immunisations in the London Charedi Jewish Community

Study Information Sheet – Key Informants, version 3, dated 16<sup>th</sup> December 2015. LSHTM Ethics Ref: 10061

N. Appendix 5: Interview topic guide for parents

**INTERVIEW TOPIC GUIDE FOR PARENTS**

**Children’s immunisations in the London Charedi Jewish Community: An in-depth qualitative analysis**

Date of visit: \_\_\_\_\_ Place: \_\_\_\_\_  
Interviewer: \_\_\_\_\_

**Interviewee(s) Socio-demographic characteristics**

Participant ID Number: \_\_\_\_\_  
Gender: Male  Female  Age (years): \_\_\_\_\_  
Ethnicity: \_\_\_\_\_ Religion: \_\_\_\_\_  
Occupation: \_\_\_\_\_ Country of origin: \_\_\_\_\_  
Relationship to child who was offered the vaccine: \_\_\_\_\_  
Gender of child: \_\_\_\_\_ Age of child (years, months): \_\_\_\_\_  
Number of members in household: \_\_\_\_\_  
Other members of household: Relationship (no names to be recorded) and their ages (years, months)  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

*If the interview involves more than one person, add the details of the second person here:*

Name: \_\_\_\_\_  
Gender: Male  Female  Age (years): \_\_\_\_\_  
Ethnicity: \_\_\_\_\_ Religion: \_\_\_\_\_  
Occupation: \_\_\_\_\_ Country of origin: \_\_\_\_\_  
Relationship to child who was offered the vaccine: \_\_\_\_\_

## Topic Guide

### ***Parents' recent experience with the childhood immunisation programme***

Tell us about your recent experience with the childhood immunisation programme (Probes – quality of service, access, information)

*Were you contacted about childhood immunisations by your GP? (Probes – letter? Text reminder?)*

*For those not up to date:*

### ***Reasons parents delay or refuse vaccination for their child***

You mention in the questionnaire that your child's immunisations are not up to date. Could you tell us the reasons for this? (Probes – convenience, access, confidence, complacency, risk/benefit)

*For those up to date:*

What are the main reasons for vaccinating your child? (Probes – protection from illness, to prevent spread of disease)

### ***Risk-benefit considerations***

What is your general view on immunisation? (Probes – benefits, concerns)

What do you know about measles? How serious do you think this is for children?

What are the benefits of vaccinating your child against measles?

### ***Information sources viewed as trustworthy***

Where do you go for information about childhood immunisation? (Probes – GP, family, friend, religious leader, media, Internet) (Note – do not collect names or any other personally identifiable data. Only record the relationship to the participant(s) and/or their professional roles)

What (if any) information do you access to find out more about childhood immunisation? (Probes – leaflets, posters, newsletters, NHS/PHE websites, other websites)

### ***Parental decision-making processes concerning childhood immunisation***

Tell us how you make decisions about whether or not to vaccinate your child? (Probes – what did this involve, weighing pros and cons)

Who do you talk to about deciding whether or not to have your child vaccinated? (Probes – husband /wife /partner, other family members, friends, GP, religious leaders, child centre, health visitor) (Note – do not collect names or any other personally identifiable data. Only record the relationship to the participant(s) and/or their professional roles)

What are their opinions, and how do these influence your views?

How do your religious beliefs influence your decision-making about childhood immunisation?

Do your religious beliefs influence other decisions you make about your health? If yes, how?

Who makes the final decision whether or not to vaccinate your child?

What are the main reasons for the decisions? (Probe – pros and cons)

### ***Barriers or promoters of vaccination***

What would make you more likely to agree to have your child vaccinated? (Probes – convenience / access - more sessions in child centres, shorter waiting times, home visits, confidence - risk/benefit, complacency - epidemic/perceived higher level of risk, household members susceptible to VPD, more information about the vaccine and vaccine preventable disease, community newsletter, advice line, Charedi nurse, assurance from religious leaders, community champions)

*[Show leaflet, ask if seen before and get feedback. Probes: information not needed/missing, language, text, photos]*

2

Children's immunisations in the London Charedi Jewish Community  
Topic guide for parents, v2, dated 9<sup>th</sup> September 2015. LSHTM Ethics Ref: 10061

O. Appendix 6: Interview topic guide for key informants

## INTERVIEW TOPIC GUIDE FOR KEY INFORMANTS

### Children's immunisations in the London Charedi Jewish Community: An in-depth qualitative analysis

Date of visit: \_\_\_\_\_ Interviewer: \_\_\_\_\_

Place: \_\_\_\_\_ Key Informant no.: \_\_\_\_\_

#### Interviewee Socio-demographic characteristics

Gender: Male  Female  Age (years): \_\_\_\_\_

Ethnicity: \_\_\_\_\_ Religion: \_\_\_\_\_

Occupation: \_\_\_\_\_ Country of origin: \_\_\_\_\_

Organisation: \_\_\_\_\_

Involvement in the Childhood Immunisation Programme:  
\_\_\_\_\_

#### Other relevant information (to be completed at the end of the interview):

Do you know anyone else who could provide insights as a key informant and might be interested in participating in the study?

Yes  No

Would you be willing to pass on details to them about our study? Yes  No

## Topic Guide

### *Involvement, experience and understanding of children's immunisation programme*

How have you been involved in the childhood immunisation programme? (*Probes – direct in terms of implementation, semi-direct e.g. in-direct community leaders*)

For those who are either directly or semi-directly involved:

How are children's immunisation organised in this community?

What is going well and what is challenging?

Have you received any feedback from parents or others about the childhood immunisation programme?

Do you send reminders/recalls about childhood immunisation to parents?

What methods do you use to improve vaccination rates? Has anything changed recently? (*Probes – Changes in commissioning to local authorities. Health visitors no longer vaccinating*)

For those indirectly involved:

What do you know about children's immunisation programme?

What is your understanding of the reason for childhood immunisation? (*Probes-purpose, benefits & risks*)

What (if any) information do you access to find out more about childhood immunisation? (*Probes – leaflets, posters, NHS/PHE websites, other websites*)

What is your view about the children's immunisation programme?

### *Parental decision-making about their child's immunisation*

Have parents discussed whether or not to vaccinate their child(ren) with you?

If, yes:

What did they ask you and what were their main concerns?

What advice did you give them?

Do you think you influenced their decision-making?

### *Reasons parents delay or refuse vaccination for their child*

Why do you think some parents do not vaccinate their child(ren) according to the recommended schedule? (*Probes – convenience, access, confidence, complacency, risk/benefit, specific VPDs such as HPV, flu, BCG*)

### *Risk-benefit considerations*

For those indirectly involved:

What is your general view on immunisation? (*Probes – benefits, concerns*)

What do you know about measles? How serious do you think this is for children?

What are the benefits of vaccinating children against measles?

### *Barriers or promoters of vaccination*

What do you think would make parents more likely to vaccinate their child(ren) according to the recommended schedule? (*Probes - convenience, access, confidence, complacency, risk/benefit, more information about the vaccine and vaccine preventable disease, epidemic/perceived higher level of risk, household members susceptible to VPD, assurance from religious leaders*)