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Tailoring Immunisation Programmes **Charedi community, north London**

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

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Contents

About Public Health England	2
Abbreviations	3
Executive summary	4
Background	5
Tailoring Immunisation Programmes for under-served communities	6
Using the TIP approach within the London Charedi community	8
Part1: Defining the research problem	8
Part 2. Stratify and prioritise target groups	15
Parental Survey	20
Part 3 Analyse behavioural patterns	21
The Planning phase, design evidence informed responses	23
Part 6 Outlining the Recommendations	27
Recommendations	28
References	34
Appendix 2 - Literature review	36

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 that 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 17th 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 Holocaust².

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 years³. The adjoining borough of Haringey was estimated to have approximately 2,844 Charedi residents in 2013⁴. 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 community⁵.

A recent population report of the British strictly Orthodox Jewish community describes it having 'extraordinary demographic growth'⁶. 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 patients⁷. 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 Jewish⁸. There was a significantly lower uptake in children (across all vaccination targets) identified as Jewish living in the south of Haringey⁹.

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 community¹⁰. 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 reside¹¹. 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 uptake¹².

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 reported¹²⁻¹⁸. A measles outbreak in 2004 in Jerusalem resulted in 117 cases, including eight hospitalisations and one death in a child with an underlying lung disease¹⁹. 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
<p>Immunisation clinics in three children’s centres: Convenient times and family-friendly facilities, resulting in a good patient experience.</p> <p>Friday afternoon summer clinics</p> <p>Sunday monthly clinics (Lubavitch)</p> <p>Wednesday weekly clinic (Norwood)</p> <p>Immuniser from the community and other staff who have a positive attitude towards the community.</p> <p>Free immunisations</p> <p>Universally available</p> <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>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).</p> <p>Not enough immunisers to meet potential demand</p> <p>Not enough admin support to enable systematic call/recall with follow up of non-responders</p> <p>Reported difficulties in getting appointments for those who want to vaccinate their child</p> <p>Traditional communication methods unsuitable 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>
Opportunities of the local immunisation programme	Threats to the local immunisation programme
<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>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>

Consider creating “community champions” for immunisations.	
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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.

Table 2: TIP initial problem statement

TIP initial problem statement – North East London 2014	
What is happening?	Recurrent outbreaks of VPDs including measles and pertussis within the Charedi community in North East London.
Who does it affect?	Un- or under-vaccinated children within the Charedi community
What are the primary effects of the problem?	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 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 3: TIP situation summary

TIP situation summary – North East London	
Problem	Low immunisation uptake among the Charedi Orthodox Jewish community in North East London
Potential primary beneficiaries	Un- and under-vaccinated children aged 4 years and under.
Key challenges	<p>9</p> <p>Due to the high proportion of children within the community, is current immunisation service provision sufficient? How do general practice services compare to those in the community? How could services be improved to further meet the needs of the community? What do the Charedi community think of immunisation services and how would they like to see them improved? Competing priorities lead to missed vaccinations.</p>
Communication	<p>Do parents know what vaccinations their children should have? Lack of access to national information campaigns means positive messages slower to spread. Negative messages can stay longer within the close knit community How to 'normalise' vaccination and increase it as a priority? Worries and misconceptions about side-effects</p>
Data	<p>What data are available to confirm sub optimal immunisation uptake and the potential for further outbreaks of VPD within the Charedi community? Are there adequate call/recall systems in place? Are children whose parents delay vaccination given further vaccination opportunities? Do details of vaccinations given outside general practice e.g. community clinics get fed back to practices in a timely way?</p>
Segmentation	What can we learn about families that immunise according to schedule and those who delay or refuse immunisations
Opportunities	Continue to build on relationships already developed with community members and religious leaders.
Community engagement	Explore opportunities to utilise community communication channels
Community specific services	Investigate the potential for increasing community specific services e.g. immunisation services on Sundays, more sessions in community venues

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?

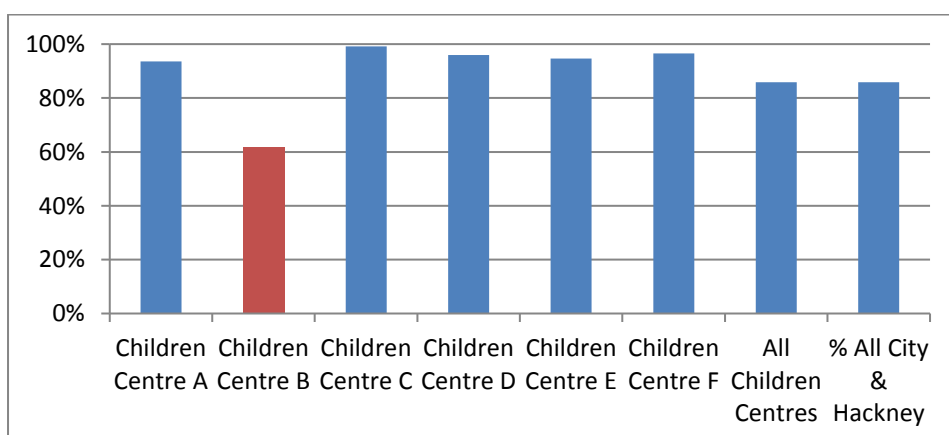
Data analyses were carried out to confirm the sub-optimal immunisation uptake and potential for further outbreaks of VPDs. General Practice provision for the Charedi community was also investigated. Details of the methods used are provided in Appendix 2.

Immunisation Uptake

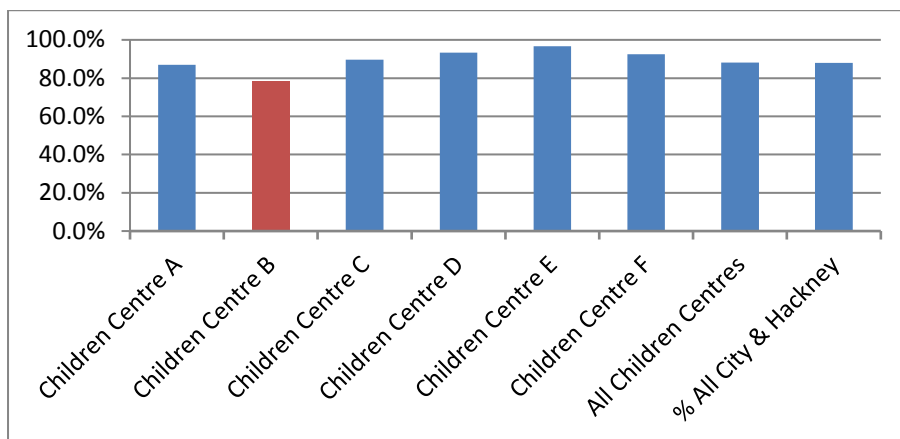
The immunisation provider at the Homerton University Hospital NHS Foundation Trust analysed immunisation uptake data of children according to the geographical location of their practice. GP practices are grouped to show their children centre association, of which there are six spaced across the London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

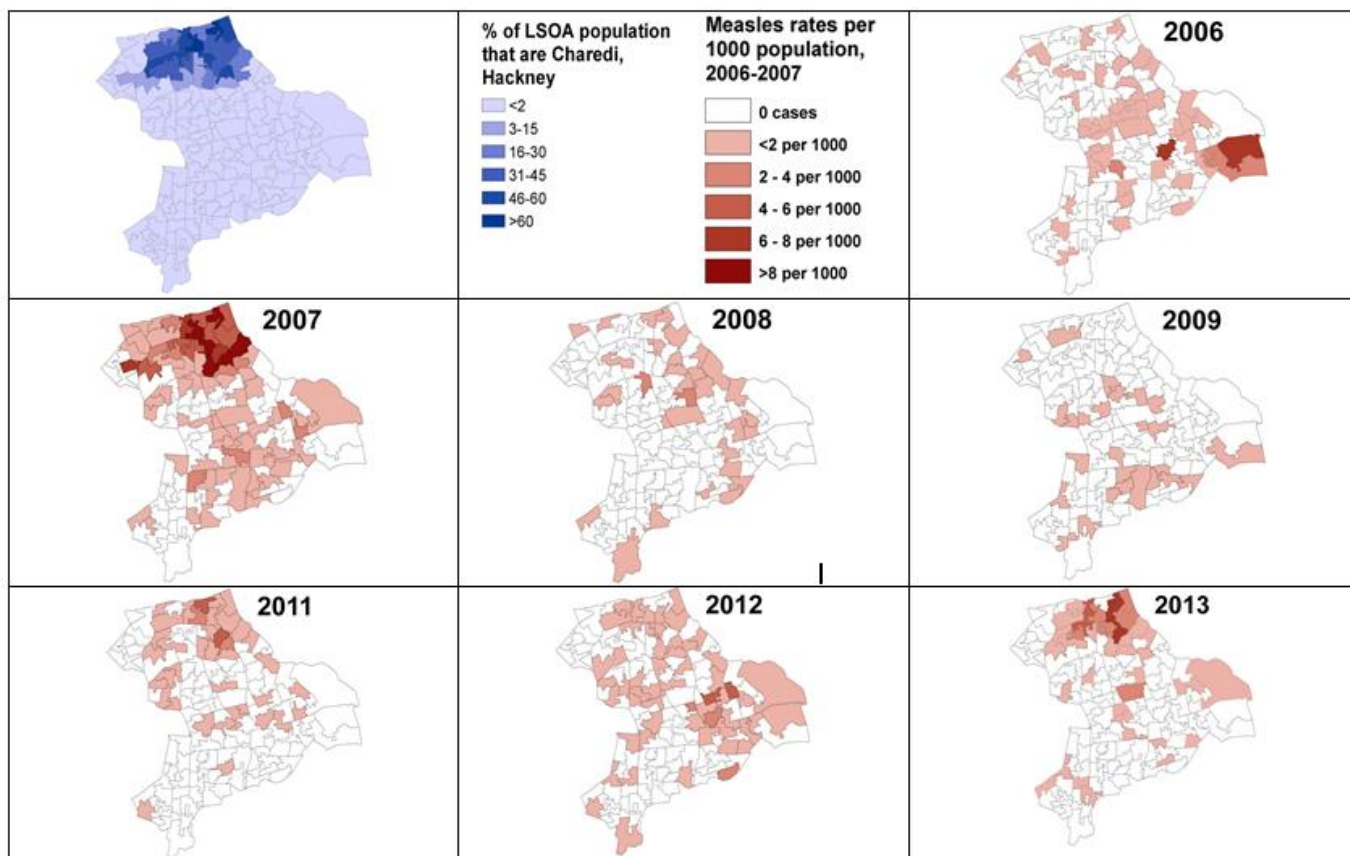
Data on measles cases in residents in Hackney was extracted from two databases used by the HPT between 2010-2013. Overall rates per year were calculated using an estimate of the proportion of the Hackney population that is likely to belong to the Charedi community as shown in a Local Authority report ³. 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.

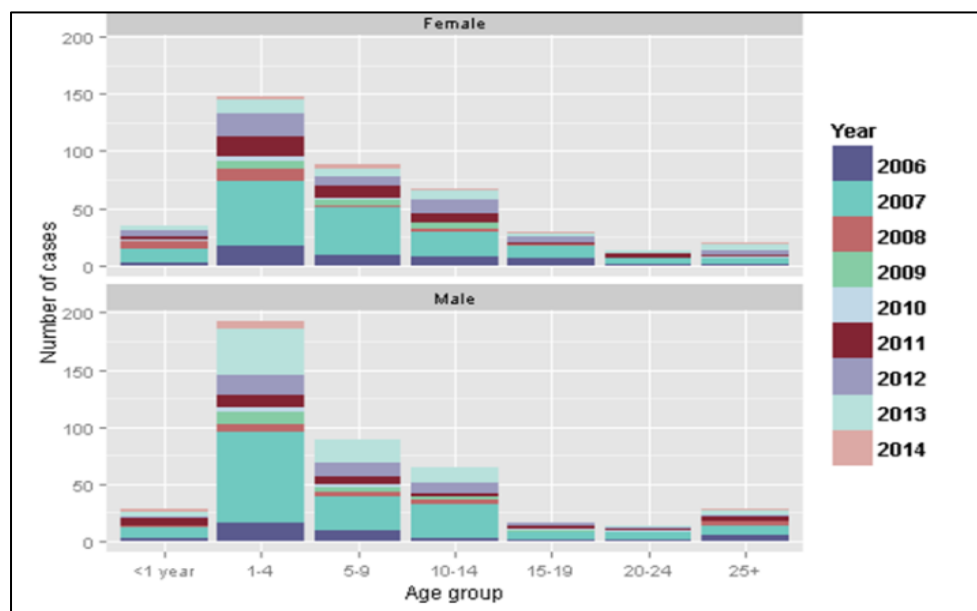


Map 1: Proportion of the population that are likely to be Charedi by LSOA (in blue) and measles rates per 1000 population by LSOA and year, London borough of Hackney 2006 to 2013; 2010 not included due to small numbers)

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.

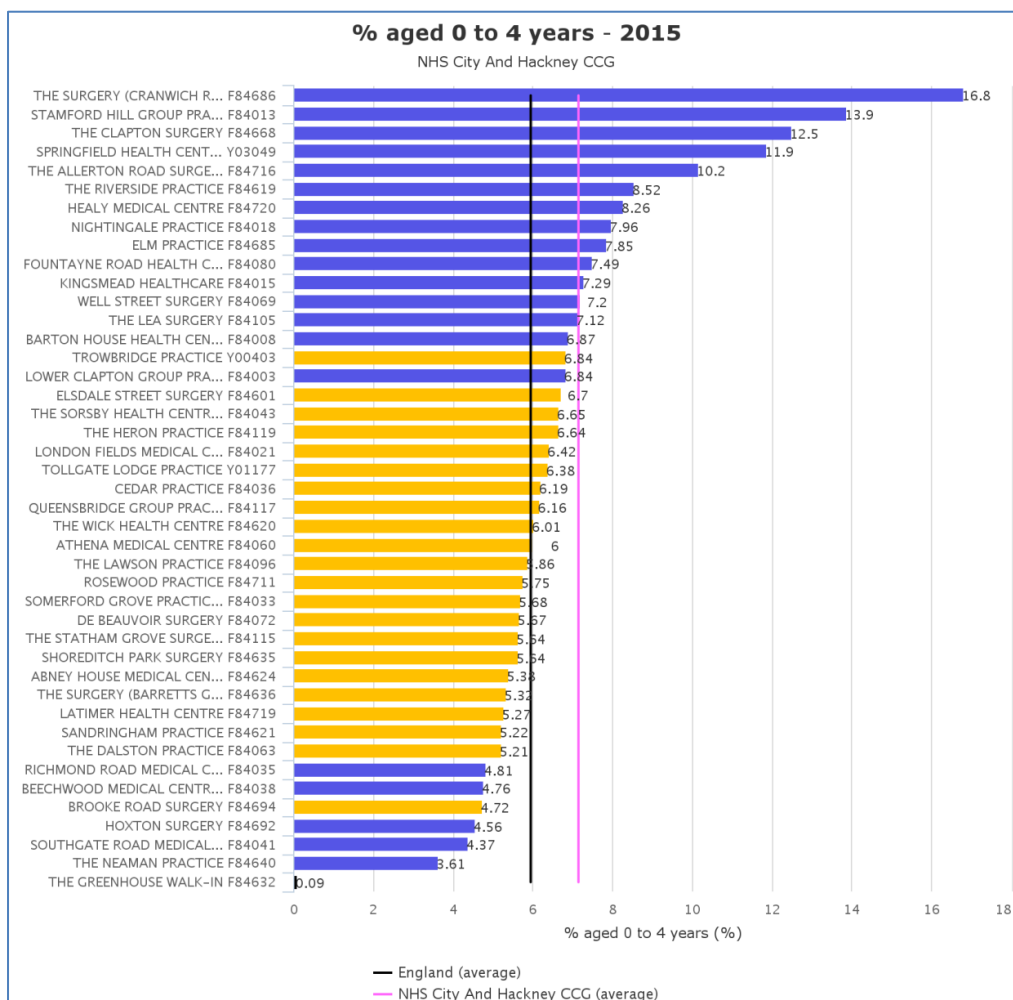
Parents whose children were not up to date with their vaccinations but did not hold negative beliefs about vaccination (50 families, 53 cases) sometimes were unaware of their children’s immunisation status. Parents also cited lack of time, particularly due to large families.

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 data²² 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.

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 overleaf.

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.

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.

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.



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

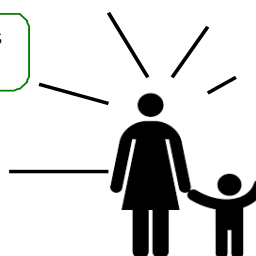
Wishes to comply with social norms in her community.

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.

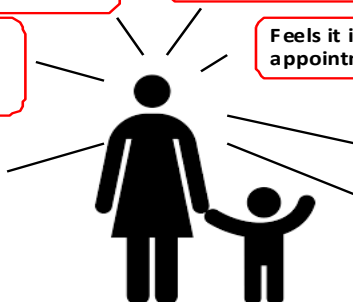
Feels that clinics are busy with long waiting time and not child-friendly.

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

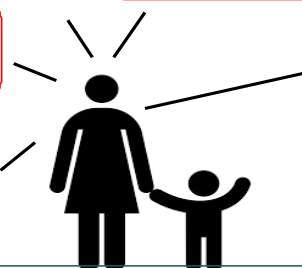
Does not feel respected by health workers.

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

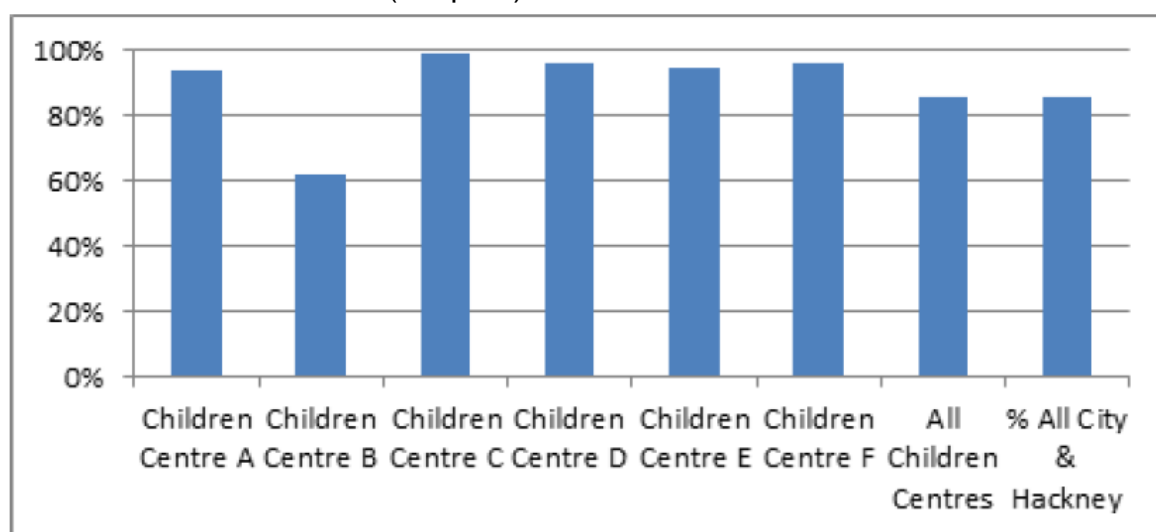
Community:

- 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

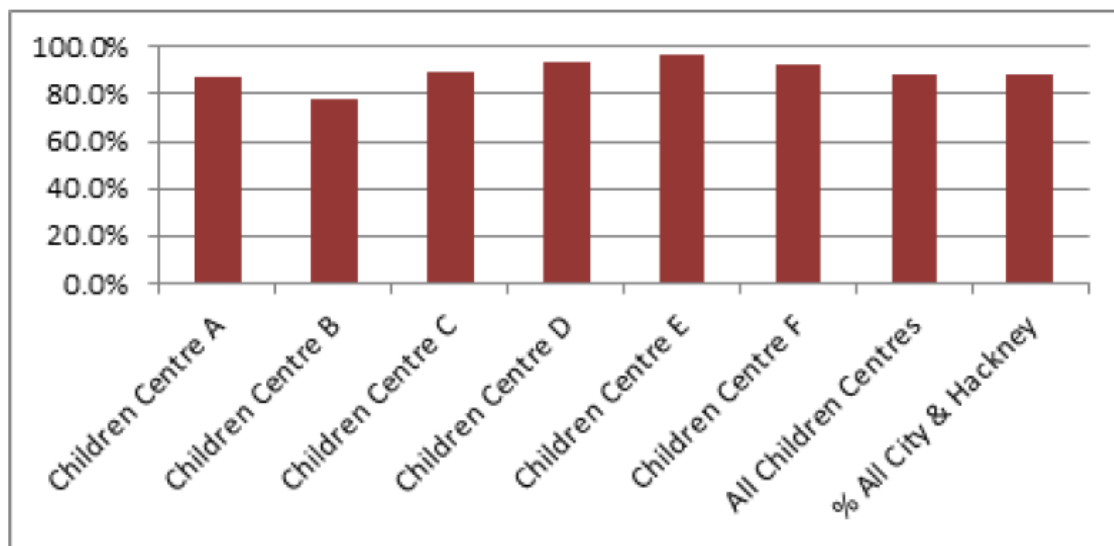
- Continue to work with healthcare team to ensure that the information provided is culturally sensitive
- Explore the nomination of community champions for immunisations.
- Consider how religious leaders could further promote and support immunisation within the community

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).

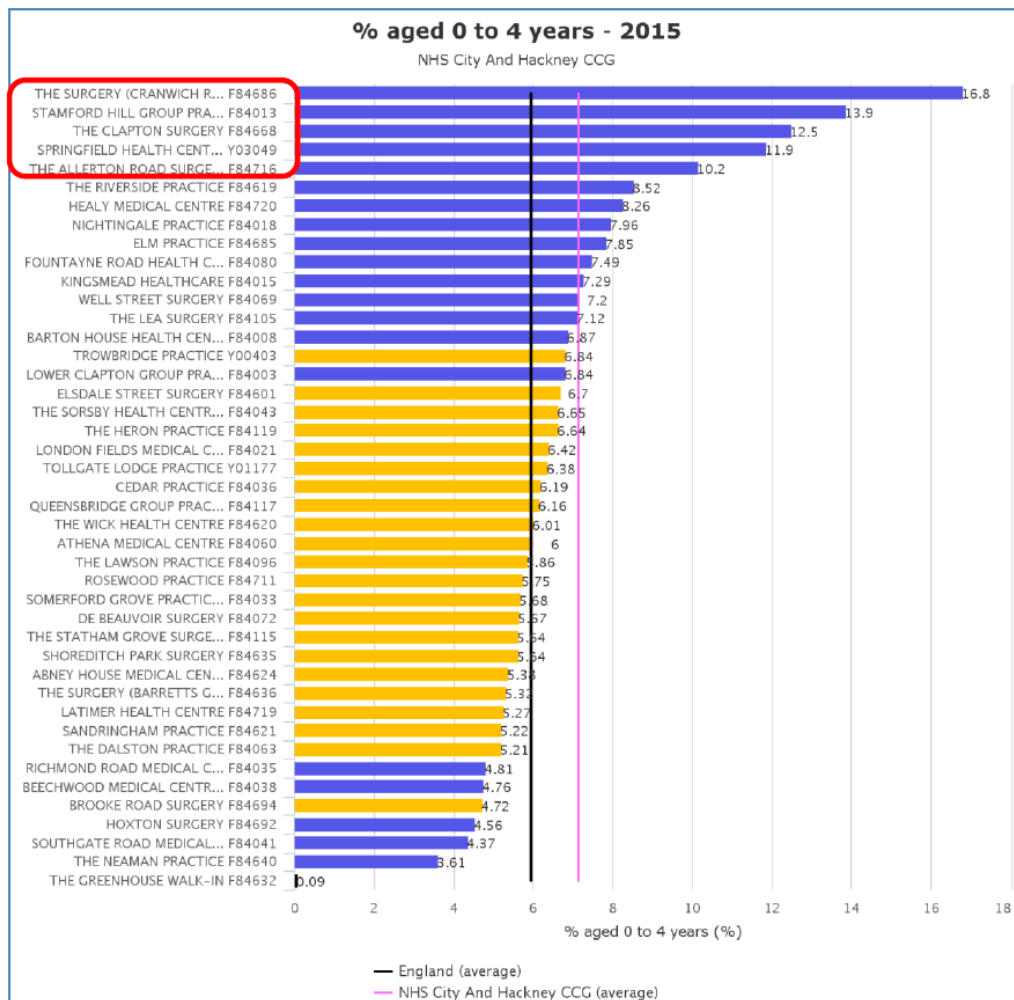


Graph 1: Coverage of the 5-in-1 vaccinations, by 1 year, in the London borough of Hackney, according to Children Centre area (quarter 4, 2014-2015)



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

References

1. 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
2. <http://www.hackney.gov.uk/hackney-diversity#charMayhew>
3. 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>
4. 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
5. 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>
6. Institute for Jewish Policy Research (October 2015). *Strictly Orthodox rising: What the demography of British Jews tells us about the future of the community*. Available at: http://www.jpr.org.uk/documents/JPR_2015.Strictly_Orthodox_rising.What_the_demography_of_British_Jews_tells_us_about_the_future_of_the_community.pdf
7. Homerton University Hospital NHS Foundation Trust (2015) Childhood immunisation in City and Hackney. Internal report
8. 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>
9. Haringey Public Health Directorate (2013). *Children receiving the recommended childhood vaccinations 2011-12*. Unpublished
10. Asnong C et al. *Lessons learned from a measles outbreak in Antwerp, Belgium 2007-2008*. *Pediatric Infectious Disease Journal*. 30 (4)
11. 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.
12. K. Muhsen et al. Risk factors of underutilization of childhood immunizations in ultraorthodox Jewish communities in Israel despite high access to health care services *Vaccine* 30 (2012) 2109– 2115
13. 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
14. 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>
15. 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>
16. Muscat M. *Who gets measles in Europe?* *The Journal of Infectious Diseases*. 2011; 204: S353-S365

17. Health Protection Agency. North East and North Central London Health Protection Unit, Annual Review 2011. Unpublished report.
18. Bosch C et al. *Mumps outbreak confined to a religious community*. *Eurosurveillance*. 2000; 5 (5). Available at: www.eurosurveillance.org/ViewArticle.aspx?ArticleId=15
19. Stein-Zamir et al. *Measles outbreaks affecting children in Jewish ultra-orthodox communities in Jerusalem*. *Epidemiology of Infection* (2007).
20. Homerton University Hospital NHS Trust (December 2015). *Immunsiation data by Children Centre*. Unpublished report.
21. Department of Health (2015) Immunisation against infectious diseases: Measles. Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/147968/Green-Book-Chapter-21-v2_0.pdf.
22. Public Health England. Practice Profiles. Available at:
<http://fingertips.phe.org.uk/profile/general-practice>.

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)ⁱ. 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)ⁱⁱ. 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 2011ⁱⁱⁱ.

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.^{iv}

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^v. 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 immunisations¹⁶. 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 identified¹². 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^{vi}. 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^{vii}. Additionally, in Belgium, these schools did not receive a MMR catch-up programme^{viii}.

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^{ix-xv}. 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^{xvi}. 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^{xvii}. 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^{xviii}.

ⁱ Gavrielov-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)

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

ⁱⁱⁱ 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)

^{iv} 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

^v 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

^{vi} 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.

^{vii} 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>

^{viii} 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**

^{ix} 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.

^x 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**

^{xi} 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>

^{xii} 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>

^{xiii} Muscat M. *Who gets measles in Europe?* *The Journal of Infectious Diseases*. 2011; 204: S353-S365

^{xiv} Health Protection Agency. North East and North Central London Health Protection Unit, Annual Review 2011. Unpublished report.

^{xv} Bosch C et al. *Mumps outbreak confined to a religious community*. *Eurosurveillance*. 2000; 5 (5). Available at: www.eurosurveillance.org/ViewArticle.aspx?ArticleId=15

^{xvi} Stein-Zamir et al. *Measles outbreaks affecting children in Jewish ultra-orthodox communities in Jerusalem*. *Epidemiology of Infection* (2007).

^{xvii} Baugh, V., Figueroa, J. Bosanquet. J., Kemsley, P., Addiman. S., Turbitt, D. Ongoing Measles Outbreak in Orthodox Jewish Community, London, UK. *Emerg Infect Dis*. 2013; 19(10): 1707–1709

^{xviii} Thorrington D et al. *The effect of measles on health-related quality of life: A patient-based survey*. *PLoS ONE* 9(9) September 2014. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4159135/pdf/pone.0105153.pdf>

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

January 2016

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Contents

About Public Health England	2
Contents	3
Background	4
Methods	5
Results	7
Discussion	12
Limitations	12
Conclusion	13
References	14

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 1st 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 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
Total number of cases (2006-2013)	156	496
Population	132849	1691759
Overall Rate per 100,000	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).



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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Table of contents

Protocol.....	1
Study title:.....	1
A. Background	3
1. Tailoring Immunisation Programmes.....	3
2. The Charedi community, north London	3
3. Immunisation coverage and associated factors	4
4. Factors associated with immunisation coverage.....	5
5. Vaccine preventable diseases	7
6. Rationale.....	8
7. Stakeholder Meeting	8
8. Partners Meeting.....	8
B. The purpose of this study.....	12
1. Study Aim	12
2. Study Objectives	12
C. Study design.....	12
1. Summary.....	12
2. Study population, recruitment and sampling	12
3. Data collection.....	14
4. Data analysis	15
D. Study Management.....	16
E. Funding and insurance.....	16
F. Ethical considerations	16
G. Dissemination and publication plans	17
H. Timeline.....	17
I. Investigators & Collaborators	18
J. Appendix 1: PHE Questionnaire	20
K. Appendix 2: Study information sheet for parents	23
L. Appendix 3: Consent form.....	26
M. Appendix 4: Study information sheet for key informants	27
N. Appendix 5: Interview topic guide for parents.....	30

O. Appendix 6: Interview topic guide for key informants 32

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 population¹. 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 17th century which spread throughout Eastern Europe with many living in rural and secluded lifestyles insulated from the outside world². 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 borough³. The adjoining borough of Haringey was estimated to have approximately 2,844 Charedi residents in 2013⁴. It is notable that the neighbouring borough of Barnet is home to the highest proportion of Jewish

¹ 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

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

³ 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>

⁴ 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

residents in England, however, only a small proportion are known members of the Charedi community⁵. 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 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 Jewish⁶. Certain practices (including these three), located in north Hackney and likely to serve the Charedi community, have lower vaccination coverage rates than other practices

⁵ 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>

⁶ 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>

servicing 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 Sisters⁷.

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 increase in temporal spacing⁸. 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_IP HV_Hib-	DTAP_IP HV_Hib-	DTaP IPV 5y	Men C 12 month	MMR1st5y	MMR24m	MMR2nd5y	PCV12m	PCV Booster24	Hib Men C booster	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)⁹. This factor was identified to be of more significance than family size, country

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

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

⁹ Gavrielov-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)

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)¹⁰. 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 Israel¹¹. 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 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.^{12,13,14}.

- **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 immunisations¹⁵. 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 immunisations¹⁶. 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 years¹⁶. Access is affected by the number of children within the family unit (reducing parental time) and services within schools. For

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

¹¹ 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)

¹² 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

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

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

¹⁵ 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

¹⁶ 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.

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 centre¹⁷. Additionally, in Belgium, these schools did not receive a MMR catch-up programme¹⁸.

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^{19,20,21,22,23,24,25}. 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 disease²⁶. 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

¹⁷ 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>

¹⁸ 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**

¹⁹ 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.

²⁰ 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**

²¹ 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>

²² 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>

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

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

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

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

communities^{27,28}. 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 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

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

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

- 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)

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

<p>(who are administering vitamin drops, etc. already to families)</p> <ol style="list-style-type: none"> 4. Service development e.g. more father friendly clinics 5. To use local advertising through free weekly newssheets 6. To work in school with young women who will be future mums 7. Consider creating “community champions” for immunisations. 	<ol style="list-style-type: none"> 3. Very close knit community making it difficult to spread positive messages about immunisations 4. Closed community 5. Resource constraints to expand and run bespoke clinics 6. Potential change of political climate
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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?

The purpose of this study

9. 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.

10. 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.

B. 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 sub-group 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.

C. 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.

D. 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.

E. 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.

F. 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.

G. 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 workshop	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

H. 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.

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 Southall, 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

I. 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"/> ₁ Yes	<input type="checkbox"/> ₂ 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"/> ₁ 16-19 years	<input type="checkbox"/> ₂ 20-24 years	<input type="checkbox"/> ₃ 25-29 years		
	<input type="checkbox"/> ₄ 30-34 years	<input type="checkbox"/> ₅ 35-39 years	<input type="checkbox"/> ₆ 40 years +		
3. What is your gender?	<input type="checkbox"/> ₁ Female	<input type="checkbox"/> ₂ 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"/> ₁ Yes Please go to Q6	<input type="checkbox"/> ₂ No Please go to Q7	<input type="checkbox"/> ₃ Not sure		
6. If, yes, please give reason(s) for choosing to immunise? <i>Please tick all that apply</i>	<input type="checkbox"/> ₁ I want to protect my child from illness	<input type="checkbox"/> ₂ I know a child who was ill from a vaccine preventable disease eg measles			
	<input type="checkbox"/> ₃ I believe vaccination is important to prevent spread of disease in the community	<input type="checkbox"/> ₄ Health Professional recommendation			
	<input type="checkbox"/> ₅ Friend or family recommendation	<input type="checkbox"/> ₆ Community member recommendation			
	<input type="checkbox"/> ₇ The facilities at the immunisation clinic were child friendly	<input type="checkbox"/> ₈ It was easy to get an appointment			
	<input type="checkbox"/> ₉ 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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

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							
9. Where would you usually go for advice on vaccination?							
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"/>		
10. How satisfied were you with the information provided?							
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"/>			
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"/>	<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

Name:	
Phone:	
Mobile:	
Email:	
Instructions	<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
Telephone: 020 3837 7084

Version 3.0

J. 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

Children's immunisations in the London Charedi Jewish Community

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

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 16th 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.

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

L. 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

Children's immunisations in the London Charedi Jewish Community

Study Information Sheet – Key Informants, version 3, dated 16th 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

Children's immunisations in the London Charedi Jewish Community

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

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.

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12. Who has reviewed the study?

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13. Contact Details

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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.

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 16th December 2015. LSHTM Ethics Ref: 10061

M. 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 9th September 2015. LSHTM Ethics Ref: 10061

N. 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

1

Children's immunisations in the London Charedi Jewish Community
Interview topic guide for key informants, version 2, dated 9th September 2015. LSHTM Ethics Ref: 10061

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*)

2

Children's immunisations in the London Charedi Jewish Community

Interview topic guide for key informants, version 2, dated 9th September 2015. LSHTM Ethics Ref: 10061

Qualitative interview results

The purpose of the qualitative interviews was to explore supply and demand side barriers and motivators to childhood vaccination, and other items raised in the parental survey in more detail. A key focus was to gain insights into and analyse Charedi community members' experiences of accessing immunisation services and their views on how these could be better tailored to their situation/or health needs.

To achieve this, we interviewed parents whose children were either not up to date, or who were unsure if their children were up to date, with their immunisations. We also interviewed key informants who had insights on this topic.

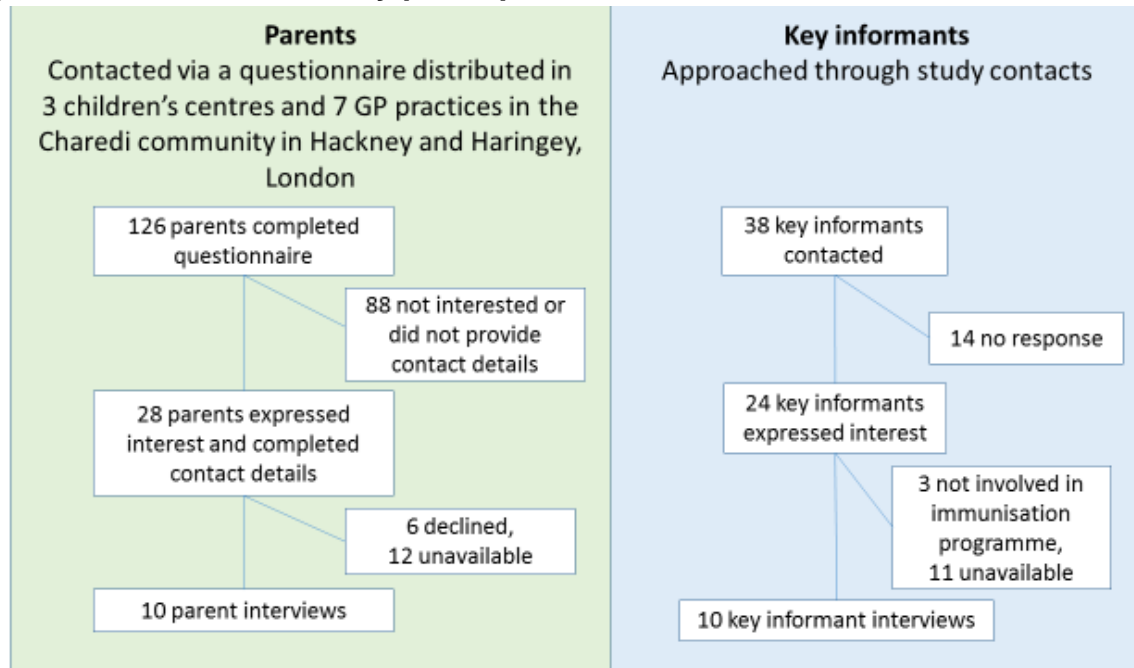
Findings

1. Recruitment

We carried out 20 interviews. We approached 28 Jewish parents, who were identified via the questionnaire and stated they were willing to be contacted for further information. Of these, ten parents were interviewed (36%) (See Figure 1). Six declined on further contact (of which four were too busy), and twelve were unavailable (wrong number, no response). Of the 18 parents not interviewed, 16 were up-to-date with their children's immunisations and two were not.

Of the 38 key informants approached, ten key informants were interviewed (26%) (See Figure 1). Fourteen key informants did not respond, three were not involved in the childhood immunisation programme in the Charedi community in Hackney and Haringey, and 11 initially expressed interest but were then unavailable.

Figure 1. Flow chart of study participants



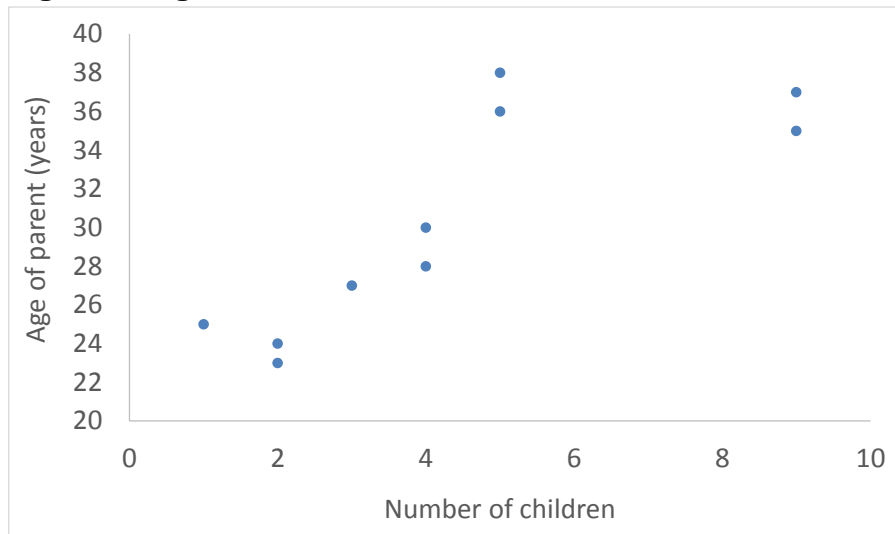
Of the ten parents interviewed, all were mothers. Their ages ranged from 23-38 years of age and the number of children ranged from one to nine. Figure 2 illustrates the distribution of age and number of children of the mothers that were interviewed.

Of the ten mothers interviewed, five had stated on the survey that their children aged under 6 years were up to date with their immunisations and five had stated they were not up to date.

During the interviews, the complexities of the status of the children's immunisations were identified:

- Five parents had fully vaccinated their children on time (although two had answered in the survey that their children were not up to date)
- One parent had fully vaccinated their children and delayed some vaccines due to medical reasons
- One parent had partially vaccinated their children on time (although they had answered that their children were up to date in the survey)
- Two parents had partially vaccinated their children but delayed some vaccines (although one had answered that their child was up to date in the survey)
- One parent had partially vaccinated some of her children delaying some vaccines and not vaccinating other children at all.

Figure 2. Age distribution and number of children of interview participants



The ten key informants interviewed included immunisation providers, a partner of a general practice serving the community, the lead Rabbi for health in the community, and employees from Hackney Council, NHS England and Public Health England.

2. What influences caregivers' use of infant and child vaccination services?

Of the five parents that had fully vaccinated all their children on time, their two main reasons for doing so were to protect their child from disease and to prevent the spread of disease. Other reasons given were because they trusted their doctor's recommendation to vaccinate, because it was the social norm and due to anticipatory regret (how badly they would feel if their child did catch a vaccine-preventable disease had they chosen not to vaccinate).

The parent that had fully vaccinated their children and delayed some vaccines due to medical reasons, has nine children. She had fully vaccinated her first four children. Her main reasons for vaccinating her children were to protect them from disease and to prevent spread of disease. Her fifth child has Down's Syndrome and she was told to delay his vaccines and he had them later. Another of her children was in a Special Care Baby Unit after birth where she was exposed to TB. She had to be treated for exposure and her immunisations were delayed as a result. Her youngest (4months) has a milk allergy and suffers from bad eczema and is currently undergoing allergy testing. Until they receive the test results she has been told to delay immunisation. Of the four parents who had either partially vaccinated their children or delayed some vaccines, one had delayed vaccines due to access issues. The other three parents' main reasons for partially vaccinating their children or delaying vaccines were due to concerns of side effects from the vaccine, concerns about too many vaccines, and a lack of perceived need for the vaccines.

We describe our findings based on the caregiver decision-making factors regarding childhood vaccination described in the TIP guide (World Health Organisation 2013, p43-48).

2.1 Environmental and institutional opportunity factors

Availability of vaccination services

The mothers interviewed stated that flexibility and ease of booking appointments were important; such as a walk-in immunisation clinic, an efficient booking system, convenient venues, including home visits, and appointment times, which may be outside of usual general practice hours, such as on a Sunday:

'My surgery has got a walk in clinic so it's quite simple... There're no appointments and no phoning up and waiting on the line for hours because you just walk in so it's quite good... The thing is I suppose people with school age children, I would have to take my child out of school for the immunisation because they don't have after school hours.'
(P4, fully vaccinated their children on time)

'It will be amazing if our [children's] centre could do it on a Sunday as well.' (P1, fully vaccinated their children and delayed some vaccines due to medical reasons)

'To make the appointment [at the children's centre] you can [get] through almost straightaway, whereas the GP [general practice] you have to stay on hold on the line, sometimes it could be about 20 minutes until you get through to the appointments line.' (P6, partially vaccinated their children and delayed some vaccines)

Characteristics and appeal of vaccination points

With ~25 infants being born into community each week, and the population doubling in size every 15 years, there is a high and growing demand on health and other services. As a result, general practice services are overstretched and there can be long waiting times to get children immunised. This is difficult for mothers who may have a number of young children, especially if the waiting area is not child-friendly.

'The challenges are actually being able to cope with the workload, the potential numbers, and as I said, because we have such an enormous number of children in this practice, we have 2.3, I think, times the average number of children under five of the average practice and so because we're resourced on a per capita basis this means that it's almost impossible to devote enough resources to actually... immunise, all the children that need to be immunised.' (K19)

'There is no appointment system so... they can wait an hour or two hours even sometimes to get an appointment... to get seen, and busy mothers haven't got the time for that.' (K17)

'[There was] a three hour wait to get seen to get vaccinated, so of course all of those things are going to be factors which are going to unfortunately be a deterrent.' (K15)

Mothers stated a preference for vaccinating their children at children's centres rather than at general practices, to avoid exposing their children to sick people in waiting areas and due to limited space for buggies. Children's centres have space for buggies and playrooms where children can play prior to vaccination and siblings can be supervised.

'In the doctor's surgery you're obviously sitting with unwell people, a lot of people, so that's not as pleasant as going to a children's centre where you're assuming it's mainly healthy people and you're not sitting in a crowded waiting room... Space for the buggy, well it's definitely more secure in the [children's] centre because it's in a gated property, whereas in the other places, in the GP, it's just an open shed where you have to bring your own lock which I don't own.' (P6, partially vaccinated their children and delayed some vaccines)

'They're [people working at the children's centre] very friendly and they're always very nice and very child friendly.' (P9, fully vaccinated their children on time)

'To a baby it makes little difference but it's even easier for me, it's in a nice comfortable surrounding without the heavy the pressure the doctor surgery, it's just not pleasant.' (P2, partially vaccinated their children on time)

2.2 Social and supportive ability factors

Knowledge of VPDs, vaccines and vaccination

Given the larger number of children per family in Hackney and Haringey, and the complex immunisation schedule, mothers sometimes had difficulty remembering which of their child needed which vaccine and when:

'It is harder with a larger family to remember who has been immunised and who hasn't.' (K16)

'We don't have all day just to think about baby.' (P2, partially vaccinated their children on time)

Social support for vaccination

As well as the time constraints parents experience due to large families, there are also Jewish holidays and Sabbath (Friday evening to Saturday evening) and times when Jewish Orthodox families, in their religious observance and commitment to the Torah and related commandments, do not use transport, money or non-emergency medical services. This can make finding an appropriate time to get their child vaccinated difficult:

'Other challenges include the frequent number of Jewish holidays... On many of the holidays there are days when they cannot... use the telephone, cannot use transport, cannot use money, so if they're being advised... your child might get a fever in a few days' time and there's a holiday coming up, then that will put people off. Similarly, this is an issue that occurs one day a week anyway on the Sabbath and which runs from sundown on the Friday to sundown on a Saturday, they cannot summon medical help unless they regard it as being an emergency.' (KI9)

There was no evidence of specific religious or cultural objection to immunisation. When discussing with parents and key informants it was evident that the Orthodox community is not unitary but contains many communities within that speak different languages and have their own cultures, and that views about childhood immunisation may differ between each of these communities.

Mothers mentioned several information sources that they referred to while deciding whether or not to vaccinate their child, including; 1) reminder aids, vaccine information leaflets and talking to health professionals; 2) speaking with family, friends and members of their community; and 3) the internet and other media.

1) Reminder aids, vaccine information leaflets and talking to health professionals

A number of mothers mentioned the helpfulness of letters from the GP and of reminder tools, such as the immunisation wall calendar, which is specific to the child and adapted to their date of birth, and a fridge magnet with information about which vaccines are due when:

'Yes, we get a letter from the GP saying that, "You're due for an immunisation," which is very convenient, and then we can book it with a nurse... They also send us a chart [wall calendar], which I have hung up, so I myself can keep track of when they need the next vaccination.' (P9, fully vaccinated their children on time)

'I also helpfully have these fridge magnets... They're really good because it lists all the vaccines and when they're given and you just tick. If you have one for each kid, then you can see if you've missed out any. So I know that they've had all... So it's quite helpful actually because you can just see it and it's so clear... I asked the health visitor after he was born if they still do them and she said they'd stopped issuing them, it was a trial period or something... Honestly, if it's in the red book I'm not necessarily going to check, but if it's on my fridge I know.' (P3, fully vaccinated their children on time)

A few mothers mentioned having seen a specific childhood immunisation leaflet adapted for the Jewish community and how they found it helpful, and in particular, the last page which explains the locations and the times of the immunisation clinics. One mother commented that the leaflet was excellent and liked that it was available

in multiple languages. However, several mothers noted that the information was out of date, and they would have liked to receive an updated leaflet.

Interviewees also mentioned speaking with their GP or midwife about childhood immunisations. Some mothers mentioned trusting their GP, others did not trust them, or were uncomfortable going to see their GP about other health concerns, as it was an issue that they had not vaccinated their child. Some mothers mentioned trusting their GP or nurse particularly if they were Jewish or a member of the Charedi community.

‘Our GP is actually an Orthodox Jewish man... So you sort of have trust that he knows what he is doing, he knows what he is saying, he knows our community, he knows what’s important and he cares for us.’ (P10, fully vaccinated their children on time)

‘The families very much like going there [the children’s centre] and I think they trust her [a community nurse], you know, many of the families trust her.’ (KI6)

‘Unless you’ve been to medical school or you just happen to have loads of knowledge because you’ve done some sort of training in medicine... Most people just have opinions. They don’t know anything about it... I tend to trust the doctors.’ (P5, fully vaccinated their children on time)

‘I don’t trust my health visitors as much as maybe I should... When it comes to vaccinations we trust our friends and hearsay more.’ (P6, partially vaccinated their children and delayed some vaccines)

‘Every time I went to see even private doctors for different things, I mean they always ask you, "Have you vaccinated?" I said, "No" so they were quite upset with me that I hadn’t and they did say to me like how important it is and I said, "Okay, thank you, thank you".’ (P7, partially vaccinated some of her children and delayed some vaccines and have not vaccinated some of her other children at all)

2) Speaking with family, friends and members of their community

Several interviewees mentioned speaking to their mothers about whether or not to vaccinate their children, and their mothers influencing them. The mothers interviewed had not felt the need to go to their Rabbi for religious guidance as to whether or not to vaccinate their child. One mother who did not vaccinate her child, due to concerns about side effects, mentioned that if her husband’s Rabbi recommended vaccination she would be more likely to vaccinate (P7, partially vaccinated some of her children and delayed some vaccines and have not vaccinated some of her other children at all).

'I did definitely speak to my mother about it [whether or not to vaccinate their child] and to neighbours... my mother's quite persuasive.' (P3, fully vaccinated their children on time)

'If I were to have a serious debate whether or not to immunise I would ask [our Rabbi]... personally I wouldn't because I know it's the right thing to do [to vaccinate], I wouldn't trouble them with that.' (P9, fully vaccinated their children on time)

'The only way I would go to, let's say, not necessarily Rabbi but let's say someone who is older, who is more wise than me in the religion, kind of like a guidance counsel almost. If I was really conflicted, let's say, about what should I do with MMR. If I hadn't already had my quite strong opinion and I was going backwards and forwards, then yes I would speak to someone who I respected who is more religious than me and say, "Is there some guidance that you can give me based on the fact that you have more knowledge than me, because I'm not learned when it comes to all the vast amounts of knowledge that is within the Jewish religion". I'm just a regular person who practises it on a daily basis, I'm not a scholar.' (P6, partially vaccinated their children and delayed some vaccines)

3) Internet and other media

Some Charedi mothers interviewed do not use the internet at home, others do, and some use the internet at work or go to internet cafes:

'Myself and most of community don't in general have access to the internet at home... If I want to look it up, I will go to internet cafe and look it all up but... I am busy.' (P2, partially vaccinated their children on time)

'The NHS website is also quite good... Sometimes it's like almost too brief, they're probably trying not to bombard you with too much information but it is quite good for general things.' (P3, fully vaccinated their children on time)

'I'm a big fan of Rabbi Google... I just Google stuff... My doctor always tells me to go to this NHS website. So, yes, very often I do... I just look stuff up, read stuff in Wikipedia or... NHS website.' (P5, fully vaccinated their children on time)

'I don't really have the time [to go on the internet], especially with my kids, running a household and working. If I would need something then I would go on it, but not just to browse.' (P8, partially vaccinated their children and delayed some vaccines)

There are community newspapers that are distributed amongst the homes in Hackney and Haringey. Several interviewees mentioned articles published in these newspapers that questioned the safety of vaccines:

‘There’s a news update that goes around to about 5,000 homes in the area and somebody had written an article why they think it’s [immunisations] no good.’ (P10, fully vaccinated their children on time)

‘There’s been articles for, for, for or against, against, against [immunisation]... There have been definitely controversy.’ (P7, partially vaccinated some of her children, delayed some vaccines and some children not vaccinated at all)

2.3 Personal motivation factors

Parental VPD perceptions

Key informants indicated that some mothers of large families feel that with their experience of raising so many children, they know best how to make choices for their children. In addition, mothers are less inclined to vaccinate their younger children with new vaccines that were not available in the past for their older children, many of whom did not get ill with the disease without the vaccine:

They [GPs] must be exhausted with families coming through and they are trying to have the same discussion and mothers saying, “Well [my son/daughter] is number 12, and actually well my other children are fine and I’ve got more experience than you have, of what’s right for my family.”... The other thing that families will say that, “I do have a lot of children and so I really know what’s best for them... and so my experience tells me that... my family are safe even though I immunise them late,” and that’s certainly another thing that mothers from the community have said to me.’ (KI6)

‘I think also nowadays especially currently there is so many vaccines and it’s consistently changing or updating the information and I think sometimes people, parents often feel that, “Well we didn’t have this when my child, my older child might have been say 8 at the time, they didn’t have, at least four of these vaccines or whatever,” which they’ve now newly introduced and sometimes I think parents feel, “Well okay if they [get] mumps they get mumps,” you know.’ (KI5)

Parental vaccine perceptions

One of the common reasons, given to health professionals, for delaying vaccination, is the parental perception that babies under one are too young and vulnerable to be vaccinated:

'[Mothers say] "I always wait until my child is at least 12 months of age."... When you ask why, they explain about the immune response, they explain about the risks.'

(K16)

'[Mothers think that] the child immune system is not strong enough to cope with so many injections in one go... they want to wait until their child is bigger and stronger.'

(K17)

'They prefer to delay vaccinations... in case there's a risk that it interferes with any of their development.'

(K18)

'A few years ago... the first immunisation was at three months and then there was another one I think at five and another one at seven or eight months... well the idea now is that we want to immunise children earlier... to protect them earlier, so it's possible that some of them get that belief from parents or grandparents and say that they may say no, the baby's too young.'

(K19)

Several mothers also expressed concern about the high number of vaccines and about immunisation overload:

'The reason I stopped giving her was also, when I went to give them the jabs, they said to me, "You've got to give like three different jabs at one go" and I was like, "Let me give her one at a time" and they didn't really accept that I'll come back like in a couple of weeks and do it, they gave me I think two jabs and each one's got like three different illnesses in it or something. I wasn't prepared to give them so many things.'

(P7, partially vaccinated some of her children and delayed some vaccines and have not vaccinated some of her other children at all)

'I still felt that I didn't need to give all those vaccines in one go, that was something really important to me... when I went and she [the health visitor] says, "For the measles you'll see a reaction", I think it was about ten days later, "With the mumps one you could see up to three weeks later a reaction" and the rubella one... I can't remember [when]... So I said, "So that's why I want to wait maybe a month to six weeks once he's finished with that and then come back for the other ones.'

(P6, partially vaccinated their children and delayed some vaccines)

Several mothers expressed concern about childhood vaccines causing adverse side-effects. One mother reported that she had developed encephalitis after each of the two doses of the MMR vaccine she had received as a child. Another mother illustrated a misunderstanding about how the meningitis vaccine worked. Two other mothers wondered why general practitioners (GPs) or Accident and Emergency staff always asked if their child had been vaccinated recently during a consultation for an illness their child was suffering. This line of questioning raised questions in their minds about the safety of vaccines and whether immunisation may have been a contributing factor to their child's ill health:

'If you give someone meningitis in a vaccine, they can also catch meningitis, that's what I feel, because you're giving them a bit of the illness inside the vaccine.' (P7, partially vaccinated some of her children and delayed some vaccines and have not vaccinated some of her other children at all)

'Why is the first question you are asked at A&E 'Has your child been recently immunised'? This raises concerns in parents.' (P1, fully vaccinated their children and delayed some vaccines due to medical reasons)

'When you go to the GP [general practice] when your child's not [well]... they do ask have they had vaccines recently. So there's obviously some sort of a link.' (P6, partially vaccinated their children and delayed some vaccines)

A few mothers expressed concerns about the effectiveness of childhood vaccines:

'We were given MMRs so why are we getting Mumps? So who is to say we are not going to get Measles and Rubella as well?' (P2, partially vaccinated their children on time)

Discussion

The main reasons given by parents for choosing to vaccinate their child were to protect them from disease, to prevent the spread of disease, trust in their doctor's recommendation to vaccinate, because it was the social norm and due to anticipatory regret. These reasons for vaccinating have been illustrated in other vaccine studies regret (Gellin B et al. 2000, Paulussen TGW et al. 2006 Wilson K et al. 2008) and the importance of a doctor's recommendation to vaccinate is widely known (Bouder F et al. 2015, Opel et al. 2013).

In terms of access, the main reasons parents gave for delaying vaccination was the difficulty in getting their child vaccinated due to large family sizes, difficulty remembering which child needed which vaccine when, long wait times, and difficulty in getting an appointment nearby.

Charedi mothers indicated difficulty in getting their child vaccinated due to large family sizes causing logistical and access issues. Jewish holidays, Sabbath and Jewish customs also posed challenges in accessing vaccination. Mothers in a study in North London in 1996 also highlighted the logistical difficulties of bringing children in for immunization with large families, with the religious calendar adding to these difficulties (Lowenthal and Bradley 1996). The complex immunisation schedule also meant that mothers sometimes forgot which of their child needed which vaccine and when. Several studies on Jewish children in Israel found that a child's birth order was

inversely related to the number of vaccines they received (Gavrielov-Yusim et al. 2012, Khitam et al 2012, Stein-Zamir et al. 2012).

Charedi mothers welcomed, and requested to continue to receive, vaccination reminders, up to date vaccine information leaflets, and immunisation reminders such as magnets and wall calendars. In a mixed methods study in 1994 on immunization uptake and parental perceptions in Jewish Orthodox community in North East London, parents requested improved information, preferably a leaflet “containing balanced information and acknowledging side-effects” (Cunninghame et al. 1994). The study by Lowenthal and Bradley also found that mothers would like more information about vaccines (Lowenthal and Bradley 1996). A review on patient reminder systems found them to be effective in improving immunization rates (Szilagyi et al 2000).

Due to the large families in the Charedi population and the high demand on services in the area, there are longer wait times at immunisation clinics. A qualitative study in the Jewish Orthodox community in North East London in 2008 found that parents were critical of lengthy waiting times (Henderson et al. 2008). Long clinic waiting times are one of a number of access-related barriers to childhood immunization (Tarrant and Gregory 2002).

In terms of access, mothers preferred a walk-in immunisation clinic or the possibility of booking an appointment quickly and easily, that the venue is close by or offer the option of home visits, that the immunisation occurs at a convenient time which may be out of normal GP hours, that there is a short waiting time to get their child vaccinated, and comfortable and pleasant surroundings with space for buggies (such as at children’s centres). In the studies by Cunninghame and Henderson parents also mentioned the inconvenience of GP practice opening times during school and work hours (Cunninghame et al. 1994, Henderson et al. 2008). In the study by Cunninghame, parents also requested reducing clinic waiting times, improving play facilities and reducing overcrowding (Cunninghame et al. 1994).

Several mothers thought that being able to have their children vaccinated at a children’s centres would be more convenient and pleasant than at the GP, as they were concerned about the sick people in the waiting area, limited space for buggies and no toys, and their children preferred going to the children’s centres. A recent study in the Salford Jewish community also found that children’s centres were valuable resources for mothers with young children (Wineberg and Mann 2015). A study by the Public Health Foundation of India found that a good ambience during childhood immunisations decreased anxiety in children and parents (Shewale et al. 2016).

Concerns about adverse side-effects as well as the effectiveness of vaccines were also raised by parents. Several interviewees mentioned local news articles that questioned the safety of vaccines, which contributed to these concerns. Jewish Orthodox parents in two other UK studies in the same area also reported concerns about side effects (Cunninghame et al. 1994, Wineberg and Mann 2015). The study by Henderson and colleagues found that participants linked low vaccine uptake to concerns over the safety of vaccines (Henderson et al. 2008). Other issues raised that merit attention were that parents did not feel that the leaflets addressed their

safety concerns. Also, asking a parent who brings a sick child to clinic whether their child had been recently vaccinated caused anxiety that the vaccine might have caused the health problem. Improved communication to address such misunderstanding should be explored in further detail.

Some mothers in this study as well as others (Loewenthal and Bradley 1996), viewed babies under one as being too young and vulnerable to be vaccinated and some felt there were too many vaccines. These parental concerns have been highlighted in other literature (Gellin et al. 2000, Madlon-Kay and Harper 1994, Offit et al. 2002).

Many mothers found the childhood immunisation leaflet adapted for the Jewish community to be helpful, especially the locations and times of the clinics and in multiple languages, although the leaflets were not always up to date. Another study, conducted in the Salford Jewish Community, also identified that leaflets in Yiddish and Ivrit were highly appreciated by parents (Wineberg and Mann 2015).

In terms of whom the mothers turned to for advice when considering vaccination, several mentioned their mothers, their GP or their midwife. None mentioned a need to consult their Rabbi for religious guidance, although one mother, who did not vaccinate her child because of safety concerns, mentioned that she would be more likely to vaccinate if her husband's Rabbi recommended vaccination. Some mothers felt uncomfortable going to see their GP as they did not agree with their GP about vaccinating their child. Other mothers reported trusting their GP or nurse because they are a member of their community. One Charedi outreach nurse, for instance, collected a feedback form from parents that noted, 'A very big bonus is having a Jewish nurse doing the immunisation who is understanding and was very caring' (unpublished). This feedback echoed other sentiments expressed in the study interviews, and endorse earlier research that notes that the physician-patient relationship is strengthened when patients see themselves as similar to their physicians in personal beliefs and values (Street et al 2008).

Given the low rates of immunization in the Jewish Orthodox community in Hackney and Haringey, it is important to explore reasons parents delay or do not vaccinate their children in order to tailor services appropriately. Our findings suggest that access to immunisation services and vaccine hesitancy are key factors that influence immunisation behaviour in this community. A number of the vaccine hesitancy issues raised by parents are not unique to Hackney and Haringey and we can draw lessons from other settings in addressing these concerns (Larson et al. 2014).

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References

Bouder F, Way D, Lofstedt R, Evensen D. Transparency in Europe: a quantitative study. *Risk Anal* 2015;1–20.

Cunningham CJ, Charlton CPJ, Jenkins SM. Immunization uptake and parental perceptions in a strictly orthodox Jewish community in north-east London. *Journal of Public Health Medicine*. 1994; 16 (3).

Gavrielov-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).

Gellin BG, Maibach EW, Marcuse EK. Do parents understand immunizations? A National telephone survey. *Pediatrics*. November 2000; 106(5): 1097-1102.

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.

Homerton University Hospital and NHS. Immunisation for children in the Orthodox Jewish community. Answering your questions. Information leaflet. [no date].

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).

Larson HJ, Jarrett C, Eckersberger E, Smith DMD, Paterson P. Understanding vaccine hesitancy around vaccines and vaccination from a global perspective: A systematic review of published literature, 2007–2012. *Vaccine*. 2014; 32(19): 2150-2159

Lowenthal KM, Bradley C. Immunization uptake and doctors' perceptions of uptake in a minority group: Implications for interventions. *Psychology, Health & Medicine*. 1996; 1 (2).

Madlon-Kay DJ and Harper PG. Too many shots? Parent, nurse, and physician attitudes toward multiple simultaneous childhood vaccinations. *Arch Fam Med*. July 1994; (3): 610-613.

Offit PA, Quarles J, Gerber MA et al. Addressing parents' concerns: Do multiple vaccines overwhelm or weaken the infant's immune system? *Pediatrics*. January 2002; 109(1); 124-129.

Opel DJ, Heritage J, Taylor JA, Mangione-Smith R, Salas HS, Dever V, Zhou C, Robinson JD. The architecture of provider-parent vaccine discussions at health supervision visits. *Pediatrics* 2013;132(6):1037–44.

Paulussen TGW, Hoekstra F, Lanting CI, Buijs GB, Hirasing RA. Determinants of Dutch parents' decisions to vaccinate their child. *Vaccine* 2006;24:644-651.

Shewale A, Joshi J, Polpakara D. Immunization anxiety related reactions: New learnings and programme experiences. July 2016. Poster presentation at Croucher Summer Course in 'Vaccinology for Public health and clinical practice in the 21st century' organised by Hong Kong University and the London School of Hygiene & Tropical Medicine.

Stein-Zamir C et al. Who are the children at risk? Lessons learned from measles outbreaks. *Epidemiology of Infection*. 2012; 140: 1578-1588.

Street RL, Krupat E, Bell RA, Kravitz RL, Haidet P. Beliefs about control in the physician-patient relationship. Effect on communication in medical encounters. *JGIM*. 2003; 18(8): 609-616.

Szilagyi PG, Bordley C, Vann JC, Chelminski A, Kraus RM, Margolis PA, Rodewald LE. Effect of patient reminder/recall interventions on immunization rates. A review. *JAMA*. 2000; 284(14): 1820-1827.

Tarrant M and Gregory D. Exploring childhood immunization uptake with First Nations mothers in north-western Ontario, Canada. *Journal of advanced nursing*. 2003; 41(1): 63-72.

Wilson K, Barakat M, Vohra S, Ritvo P, Boon H. Parental views on pediatric vaccination: the impact of competing advocacy coalitions. *Public Understanding of Science*, SAGE Publications, 2008, 17 (2), pp.231-243.

Wineberg J and Mann S. Salford Jewish community health research report 2015.

World Health Organisation. The Guide to Tailoring Immunisation Programmes (TIP). Increasing coverage of infant and child vaccination in the WHO European Region. 2013. Available at: http://www.euro.who.int/_data/assets/pdf_file/0003/187347/The-Guide-to-Tailoring-Immunization-Programmes-TIP.pdf