MEETING REPORT

Individual decision-making and childhood vaccination

24 May 2013, Stockholm, Sweden

Introduction

The European Union (EU) aspires to be measles-free, which will require high vaccination coverage across the entire region [1]. Yet in recent years there have been fairly large measles outbreaks in Europe; one very plausible interpretation from the 2011 outbreak in France, for example, is that this is due to 'persistent suboptimal vaccine coverage'[2]. Among the many important reasons for suboptimal vaccination coverage, a significant one that certain population segments actively decide not to vaccinate.

ECDC has previously investigated key barriers to vaccination among hard-to-reach populations [3], and yet it is commonly observed that in addition to such populations, some segments of the general European population may also be sceptical towards vaccination. In order to explore this topic in greater depth, ECDC organised a meeting which took place in Stockholm on 24 May 2013. The aim was to exchange cross-disciplinary perspectives, from epidemiology, anthropology, sociology and behavioural psychology, in order to explore the issue of measles, mumps, and rubella (MMR) vaccine refusals among the European 'middle classes'.

In particular, objectives for this meeting workshop included:

- to explore the key drivers behind recent trends in measles epidemiology and vaccination coverage in Europe
- to identify and conceptualise the myriad social and political factors that affect individual decision-making as concerns vaccination
- to identify and examine best practices in public health for monitoring and addressing public mistrust in vaccines
- to identify potential ECDC activities in this field.

This report briefly highlights the principal themes discussed in the meeting and identifies avenues for further exploration. The meeting was conducted under Chatham House Rules, meaning that participants could express any opinion they wished with the knowledge that the meeting report would not attribute statements to particular individuals.

Stockholm, October 2013

Background: perspectives from medical sociology on vaccination uptake

Measles continues to be highly prevalent in Europe. As of May, 2013, 8 127 cases of measles were reported over the previous 12-month period in the EU, with 95% of the cases coming from France, Germany, Italy, Romania, Spain and the United Kingdom.

The control of vaccine-preventable diseases like measles depends upon herd immunity, but pursuing wide vaccination coverage invariably raises ethical dilemmas [4]. Principal among them is the paradox that although overall population health undoubtedly improves with higher vaccination coverage, it also implies that a greater number of individuals are exposed to the potentially harmful side-effects of vaccination, however rare these may be. Where widespread public concern about the safety and value of vaccinations exist [5], individuals may re-assess for themselves whether the benefits from vaccinating their children outweigh the risks.

It is sometimes assumed that a key factor in public resistance to vaccination is a poor technical understanding about vaccination among the general public. Risk benefit analyses are complex and as such, it may be easy for people to over-estimate the risks and under-estimate the benefits. According to this line of reasoning, if the public were to be better informed about the true safety profile of vaccines, then most objections would be overcome and vaccination coverage would increase. Thus, one key goal for public health has been to find better ways of informing the public about the evidence surrounding vaccination [6].

Unfortunately, these approaches have sometimes not incorporated insights from nuanced sociological analyses of what might be best termed 'vaccine critical groups'. These analyses repeatedly point to the role that values, beliefs, and social and political contexts play in informing individual perceptions of risk [7-9]. Individuals do not always perceive risks in the same way as epidemiologists or actuarial scientists calculate them to be. In addition to scientific findings (often filtered through the popular media), people incorporate a wide range of factors into their decision-making on childhood vaccinations, such as personal and cultural values, their assessments of the health/fitness of their child, their family's health history, or the extent to which they trust governments, pharmaceutical companies, and their family physician [10].

Therefore, it is not necessarily that people misunderstand vaccinology so much as they re-interpret it to place a greater emphasis on factors more important to them individually. Ironically, pro-vaccination messages tend to emphasise the need for parents to educate themselves before having their children vaccinated [7], but this is of questionable benefit given that the evidence is relatively weak that awareness of vaccine safety issues or overall levels of education leads to higher vaccination uptake. Pro-vaccine communication rather than genuine dialogue to understand a parents concern can actually frustrate a questioning parent and aggravate the anxieties.

Discussion points

Several key themes emerged from the meeting, which are summarised below.

Vaccine hesitancy

Terminology is important when discussing individual decision-making and vaccination. Although it is fairly common to see usage of terms like 'vaccine refusals', such terms tend to polarise the issue rather than add nuance. Participants noted that 'vaccine hesitancy' best captures the idea that in many circumstances, decision-making is not polarised. Instead, there is a continuum of people's perspectives on vaccination, ranging from a few polarised individuals at the extreme but many more people somewhere in the middle, somewhat uncertain and ambivalent about vaccination decisions [11]. People that accept vaccination might still have serious concerns about long-term side effects, whereas those who reject vaccinations might doubt their decision and worry about regretting it should they or their children come to be infected by a vaccine-preventable disease in the future. Owing to the uncertainty that most people have concerning vaccination decisions, many are highly susceptible to influence by sources such as the media, social networks, and, notably, the advice of health professionals.

News of adverse events, new research, policy changes, new vaccine product introductions, etc., can all prompt rumours and media reports raising concern, which in connection with contextual factors such as trust in organisations or socio-economic aspects can potentially lead to greater vaccine hesitancy. This phenomenon was discussed in light of research from other sectors on the social amplification of risk [12]. The literature offers intriguing avenues for extended public health research into the factors driving public perceptions of risk.

Monitoring vaccination uptake and vaccine hesitancy

Many meeting participants noted the relatively long time-lag between reduced public confidence in vaccinations and lower vaccination coverage. Waning public confidence in the safety of vaccinations can take months or years to manifest in higher rates of vaccine refusals and consequent outbreaks of vaccine-preventable diseases [13]. Thus, monitoring vaccine confidence is an essential activity, but one that must be undertaken with a long-term perspective. Conversely, upsurges in rates of vaccine-preventable diseases might be used as a gauge of vaccination uptake rates over the past several years. Where upsurges are obvious for diseases like measles, which has high vaccine efficacy, clear diagnostics and a rapid attack rate in unvaccinated communities, these upsurges could indicate that other vaccine-preventable diseases could also be on the upswing.

One key result of the above insight is that relying upon reported vaccination coverage rates alone is potentially problematic: even good overall national vaccination coverage rates do not guarantee that a country is 'immune' to an explosive outbreak, which could be due to regional variances of vaccination coverage as well as, in the case of measles, poor second-dose vaccination coverage data.

It might even be necessary to supplement vaccination coverage data, and if so then assessing public attitudes increases in importance. Sampling public attitudes to vaccination offers not only the opportunity to assess broad trends, but also the possibility to probe them. It is an often overlooked aspect of vaccination coverage, for example, that many people may not be getting vaccinated simply because they cannot recall their last vaccination or their next scheduled one, as a health barometer survey from France in 2010 revealed[i]. This was one common theme from the meeting – vaccine hesitancy certainly exists, but structural barriers, such as the lack of efficient systems for reminding parents and adults of their scheduled vaccinations may also contribute to suboptimal vaccination uptake.

Multiple participants highlighted that surveys in which knowledge, attitudes and beliefs towards vaccination are explored can act as interventions themselves, reminding people of the availability or importance of vaccinations. Attitude surveys sometimes focus on perceived vaccine risks, which could inadvertently influence decision making. As such, surveys could probe into perceived vaccine benefits and not solely focus on risks.

In today's digital age, many participants explicitly identified the internet and social media as very important for influencing public opinion on vaccines. Developing means for monitoring vaccine confidence via social and mass media, as well as better understanding the role of influential websites, will likely become increasingly important for assessing the dynamics of vaccine hesitancy.

Theorising individual decision-making: the role of fear and trust

It has already been noted that vaccine decisions are made along a continuum of potential decisions, rather than being simple binary decisions (e.g. to always vaccinate, or to always not vaccinate). Social contexts, social media, and other information sources will, as mentioned in the sections above, inevitably influence decision-making, but so too can structural issues such as whether or not people remember that vaccinations or booster shots are required.

Ultimately, however, each individual will come to their own conclusion – sometimes vastly differing ones even in the same socio-cultural context. It is therefore important for public health practitioners to consider how the wide range of external stimuli that exist are ultimately processed by individuals. Of the many available theoretical models for assessing individual decision-making, one prominently featured in the discussion was the health belief model, through which perceived susceptibility and severity of a disease are considered alongside perceived benefits of an intervention as well as barriers to adopting that intervention [14, 15].

Based upon the central tenets of this model, discussion focused on the observation that many people appear to under-estimate the severity of vaccine-preventable diseases like measles, likely because they have not come into close contact with the disease and/or are not aware of the severe complications that can arise. Similarly, whereas people may expect that overall vaccination rates are high, they might assume that this herd immunity offers a form of protection, thereby averting the need to incur any personal risks in getting vaccinated. This leads to a significant ethical dilemma, whereby the individual risks for vaccination are weighed against the societal benefits of ensuring herd immunity.
Meanwhile, it could be that many people over-estimate the risks of vaccination, likely due to the fall-out of incidents such as the Wakefield affair, through which a reported link between MMR vaccination and autism was subsequently demonstrated to be the result of methodologically and ethically flawed research [16]. Supporting this

[i] Institut national de prévention et d'éducation pour la santé. Les comportements de santé des jeunes: analyses du Baromètre santé 2010 http://www.inpes.sante.fr/Barometres/barometre-sante-2010/comportement-sante-jeunes/telechargements.asp

observation were examples from studies, such as one which demonstrated that fear of vaccination side-effects is the most frequent reason for non-vaccination among healthcare workers. How a vaccine confidence gap in one particular vaccine affects the confidence in other vaccines requires more investigation. The state of maturation of a vaccine program is likely an influential factor in whether levels of vaccine coverage are maintained, following negative vaccination reports in social media and the press, a point which was discussed at the meeting. There have not been notable decreases in childhood program vaccination coverage to date following the increased risk of narcolepsy associated with the pandemic H1N1 vaccination in Europe [17].

Counter-balancing fear is trust in the safety of vaccination, which could be acquired through interactions with healthcare workers, positive experiences in vaccination, as well as broader trust in the scientific institutions in society. One important trend in past decades, however, is that some segments of society have lost their trust in medical research, which can be linked to a wide range of incidents, such as the BSE (Bovine spongiform encephalopathy) crisis in the UK, which led the House of Lords noting that there was a crisis of public trust in public health science [18]. From this perspective, further attention may need to be paid to broader trends in public trust in science and how these connect to trends in attitudes toward vaccination.

The role of healthcare workers

As was repeatedly mentioned during the meeting, the most important and well trusted source of information in parent's decision-making process is the healthcare worker. Physicians and nurses generally have positive attitudes toward vaccination, and as such their key role as intermediaries in the healthcare system deserves greater attention. However, all practitioners do not verbalise positive vaccination messages to patients, which influence patients' decisions to vaccinate [19].

ECDC presented its work addressing this critical audience, noting that during previous ECDC expert meetings aimed at identifying key interventions that contribute to increase vaccine uptake, investing in healthcare practitioner's education to communicate more effectively with their patients on immunisation was highlighted as an important intervention. In this context, ECDC has developed tools to support the communication between healthcare providers and patients, in order to more effectively address patient's concerns and questions, and also to better understand how people wish to receive the information about vaccination.

Structural barriers to vaccination

Aside from the issue of vaccine hesitancy, participants highlighted that low vaccination coverage in some instances is related to the obstacles presented by everyday life. People might forget that vaccinations are due, or it might simply be that it is too inconvenient, costly, or problematic for people to arrange to get vaccinations. As mentioned, the state of vaccination program maturation drives vaccine coverage.

Research from Sweden indicates that there are instances where there is a discrepancy between people's attitudes towards vaccination, which can be quite favourable, and what they do in practice [20]. As such, one key role for public health should be to seek to eliminate as many barriers to vaccination as possible.

Communication

Given the strong role that the media and social media play in influencing people's perspectives on vaccination, a point of emphasis in the discussion related to the way in which public health agencies communicate the risks and benefits of vaccination. Participants acknowledged that communication needs to carefully convey risks as well as benefits, and that health agencies should seek to establish roles as 'honest brokers' who seek to neutrally and objectively communicate facts. Whilst some discussion assessed whether it would lead to higher vaccination rates if public health messages about the danger of vaccine-preventable diseases were stronger, most participants agreed that this could cause a backlash, and that stoking fear should not be an objective of public health.

Conclusion: towards a pan-European approach

This meeting established the importance of viewing vaccination decision-making as a continuum, through which people are largely ambivalent about their personal choices to vaccinate or not. Based on the discussions highlighted in the previous section, several areas for continued action by ECDC were discussed. Participants noted the role that ECDC could play a role in fostering a pan-European perspective on the issue through:

- facilitating public health agencies in Europe by encouraging research and further attention to the issue as well as to the need of combining insights from multiple disciplines [21].
- exploring the feasibility of establishing methodologies, and potentially also programmes for enhancing European capabilities to assess social media and internet trends with regards to how positively or negatively vaccination messages are treated.
- sampling approaches for assessing public attitudes towards vaccination
- defining strategic approaches for facilitating public health engagement with mass media and the internet.

There is sometimes a gap between the expertise in public health agencies, which tends to be concentrated in the areas of medicine and epidemiology, and the expertise required to address vaccine hesitancy, which requires insights from a wide range of additional disciplines, including the social and behavioural sciences and health economics. Participants noted that ECDC could play a role in bringing together these often disparate communities.

Meanwhile, it was noted that ECDC should continue to address healthcare workers as an influential source of objective information about vaccinations. Participants furthermore stressed that structural or health system barriers may in some cases be driving low vaccination coverage rates.

Finally, participants highlighted the importance of eventual time-lags between negative media vaccine publicity and trends in vaccine hesitancy or declines in vaccination coverage. Where the latter occur, assessments should be made with regards to whether certain pockets of susceptibility exist, and whether interventions or tailored campaigns in these areas might be useful. Even where overall national or regional vaccination rates look good, it should be remembered that heterogeneity in these rates could still mean that many are vulnerable to vaccine-preventable diseases.

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Appendix 1. Meeting agenda

May 24, 2013

08:30 – 09:00	Introductions and coffee
09:00 – 09:10	Welcome - Piotr Kramarz, Office of the Chief Scientist, ECDC
09:10 – 09:20	Introduction and background to the meeting - Pierluigi Lopalco, Jonathan Suk, ECDC
09:20 – 10:00	Greg Wallace, CDC. *Measles: Immunization's canary.*
10:00 – 10:40	Heidi Larson, London School of Hygiene and Tropical Medicine *Measuring the vaccine confidence gap.*
10:40 – 11:00	Coffee
11:00 – 11:40	Cornelia Betsch, University of Erfurt. *The vaccination decision: a theoretical perspective.*
11:40 – 12:20	Mircea-Ioan Popa, "Carol Davila" University of Medicine and Pharmacy, Bucharest. *Field short-report: Attitudes and knowledge of pregnant women.*
12:20 – 13:00	Christine Jestin, National Institute for Prevention and Health Education, France. *Perceptions and reasons for non-vaccination in France. Example: Measles.*
13:00 – 13:40	Lunch
13:40 – 14:20	Lisen Arnheim Dahlström, Karolinska Institutet. *Socioeconomic factors influencing vaccination uptake in an opportunistic programme.*
14:20 – 15:00	Mike Hudson, Public Health England: *Parental decision-making over MMR, a decade after Wakefield.*
15:00 – 15:10	Coffee
15:10 – 15:30	Andrea Würz. *ECDC work on supporting effective communication for increasing immunisation uptake.*
15:30 – 16:30	Open discussion: Amy Leval, Smittskydd Stockholm.
16:40 – 17:00	Closure of meeting and departures

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