

Let's talk about protection

enhancing childhood vaccination uptake



Communication action guide for health care providers —

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enhancing childhood vaccination uptake



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“Outbreaks of measles across Europe in recent years are a sign that immunisation programmes are not reaching all children. This ECDC guide supports action by health care providers with communication advice and tools.”

Dr Marc Sprenger, Director, ECDC



Introduction

Welcome to the European Centre for Disease Prevention and Control (ECDC) childhood vaccination communication action guide. It provides practical peer-reviewed advice and evidence-based guidance for health care providers (HCPs) involved with immunisation servicesⁱ on ways to increase childhood vaccination uptake. This advice and guidance is delivered by giving voice to the thoughts, knowledge and insights of parents, social marketersⁱⁱ, health promoters and other health service and public health experts. The advice aims to help HCPs gain insights into the behaviours and choices of different stakeholders and identify ways to better address concerns and obstacles to vaccination uptake.

The crucial role of health care providers

Multiple studies show that in all European Union (EU) countries, HCPs are identified as the most important and trusted source of information on how to be protected from vaccine-preventable diseases (1-3). This is particularly true for parents with the most questions and concerns. HCPs' personal credibility and trusting relationships place them in unique positions to help support parents in understanding vaccination and choosing to get their children protected and in turn to protect others by being vaccinated.

ⁱ Health care providers as used here includes all those involved in vaccination programmes, including doctors, nurses, pharmacists, public and community health workers and mediators (e.g., Roma health mediators).

ⁱⁱ Experts in behavioural communication and change.

Today's vaccination challenges

As regards vaccination, Europe has some big challenges! Vaccination rates for some preventable diseases in many EU Member States have dropped below recommended coverage rates needed to sustain protective community or so-called 'herd immunity'.ⁱⁱⁱ This has left large pockets of susceptible populations^{iv} in many EU countries and once well-controlled diseases are now reappearing (4). In 2011, for example, more than 30,000 cases of measles were reported in EU and European Free Trade Area (EFTA) countries. Cases were reported in all countries, except the island nations of Iceland and Cyprus. The outbreak of measles in the western part of Europe was amongst the largest in the world in 2011 (4), with the highest number of cases in Germany, France, Belgium, Austria and Denmark. This is a public health failure. Measles is completely preventable and Europe has committed to eliminate its transmission by 2015. Measles is not a harmless disease! One fifth of cases in the UK needed hospitalisation and eight people died from the disease in the EU in 2011. The key factor contributing to the European measles epidemic is sub-optimal vaccination uptake and reach that has left large population groups either unprotected

ⁱⁱⁱ Herd immunity: A situation in which a sufficient proportion of a population is immune to an infectious disease (through vaccination and/or prior illness) to make its spread from person to person unlikely. Even individuals not vaccinated (such as newborns and those with chronic illnesses) are offered some protection because the disease has little opportunity to spread within the community. Also known as community immunity. (www.cdc.gov/vaccines/about/terms/glossary.htm#commimmunity)

^{iv} Even in countries with high coverage rates the number of unvaccinated will accumulate over time (4) and poorly protected sub-national pockets of vulnerable people can be found.

or under-protected. The majority of European cases (90%) were amongst adolescents and adults who had not been vaccinated or for whom vaccination history was not reported (4).

Unprotected and under-protected populations

Recent studies have identified a range of characteristics of unprotected and under-protected (unimmunised and under-immunised) populations (5,6). In broad terms four key population groups^v have been identified:

'The hesitant' – those who have concerns about perceived safety issues and/or are unsure about needs, procedures and timings for immunising;

'The unconcerned' – those for whom immunisation is considered a low priority with no real perceived risk of vaccine preventable diseases;

'The poorly reached' – those with limited or difficult access to services, related to social exclusion, poverty and, in the case of more integrated and affluent populations, factors related to convenience; and,

'The active resisters' – those with personal, cultural or religious beliefs which discourage or exclude vaccination.

^v In the guide, concerns and advice for HCPs from representative voices of the first two groups (the 'hesitant' and 'unconcerned') are presented in Section 1. Concerns and advice from the last two groups ('the poorly reached' and 'active resisters') are included in Section 4 as so-called 'hard-to-reach' groups.

The focus, aim and approach of this action guide

The focus of this action guide is on behaviour-related communication. Its aim has been to identify ways to help HCPs help all parents to want and get their children protected by vaccination as a desired behavioural goal and outcome, particularly those in population groups whose children are currently un- and under-vaccinated. The development of the guide has included both primary and secondary research. We contacted people who are making decisions, studying, writing and advising about protective vaccinations. We interviewed them, organised focus groups, questionnaires and used other data gathering methods in an attempt to better understand their decision-making processes (see Annex 1 for a full description of methodologies applied). We explored issues related to access to and understanding of relevant health information about vaccine-preventable diseases and risks. We sought clarity on where people obtain information, who they trust and who and what influences their vaccine-related decisions.

Capturing insights and advice

Through this process we have gained qualitative insights into different groups' 'vaccination journeys'^{vi} and importantly, have obtained advice about how those 'journeys' could be made easier. The insights and advice

^{vi} The steps people follow from learning about vaccines, getting answers to their questions, deciding (or not) to get their children vaccinated, navigating their way through their health care systems, consulting with their providers, getting, delaying or refusing to get their children immunised, dealing with side effects, following up with schedules, etc.

which emerged from this process were further developed with ‘recommendations to improve vaccination uptake’ made in peer-reviewed and ‘grey’ literature publications and websites identified through Pub-Med and Google searches (see Annex 1 and references). All these sources were then used to develop the ‘advice’ given by different stakeholders. Initial drafts of the ‘advice’ were amended and redrafted based on reviews and critiques by relevant stakeholders (see Annex 2 for a full list of expert interviewees and reviewers). In this way the guide presents evidence-based and peer-reviewed but ‘simulated’ conversations between stakeholders and health care providers. Three key messages for health care providers emerged from this process:

- a) make vaccine communication more of a two-way information exchange;
- b) keep the focus of discussions on the benefits of ‘getting protected and protecting’; and
- c) make the settings and systems in which people obtain vaccinations simpler, more accessible and easier to navigate.

Two-way communication

Stakeholders noted that health care provider communication, often due to time constraints, was generally too focused on one-directional communication and the sending of well intentioned but uniform messages to all. HCPs were advised to place more emphasis on dialogues – two-way conversations – which first elicit information about parents’ specific concerns and anxieties

and then adapt and customise messages to the identified needs of individuals and groups.

Keep the focus on protection

While vaccine safety issues need to be directly and clearly addressed and reassurance given where parental concerns exist, parents and other experts called for HCPs to keep the focus of vaccination discussions on the benefits of protection. People need to be fully aware that when they get their children vaccinated that they are protecting them, and the communities in which they live, from serious and potentially deadly diseases.

Effective design and reconfiguration of services

Stakeholders uniformly reported a need for improving the design and provision of services and delivery systems. Advice calls for more attention to be paid to costs, location, staffing, transport, scheduling and timing as key determinants of vaccination programme uptake and success. ‘Vaccination journeys’ need to be made easier.

Evaluating the guidance

All experts interviewed (Annex 2) provided advice on evaluating the impact of this guidance on health provider communication and behaviour. All indicated that the key outcome measure should be quantitative data that showed changes in vaccination uptake (e.g. MMR- measles, mumps and rubella) by the different target groups. They also emphasised the importance of disaggregated data that could be used to monitor and compare uptake rates related

to different providers, institutions, communities, sub-national areas and social groups.

In addition to the above, experts identified a variety of process measures and ‘checklists’ to determine:

1. whether providers were adopting the communication and re-design advice provided by parents/carers, social marketers, peers and so-called ‘hard-to-reach’ populations proposed in this guidance;
2. whether providers were maintaining their vaccination information and administration skills up-to-date; and,
3. the impact of guidance catalysed changes on different target group perceptions and behaviours related to protective vaccination programmes.

A summary of the expert advice on criteria, indicators and ‘checklists’ for outcome and process evaluation of this guidance is presented in Annex 4.

Organisation of guide

Part I of this action guide is dedicated to presenting stakeholder feedback and advice to health care providers on ways to improve communication and service/delivery system designs. Advice is presented from the perspective of parents, health promoters, social marketers, peers and representatives of so called ‘hard-to-reach’ populations. Sample questions and answers^{vii} to common concerns are provided throughout the text.

^{vii} Questions and answers unless otherwise noted have been adapted from *Provider resources for Vaccine Conversations with Parents* (7).



Part II includes information hand-outs, schedules, forms, graphics, stories and website references that HCPs can use to support their conversations with parents, grandparents and carers.

Finally, this guide is designed to be ‘a living document’, so we encourage you to give us feedback on its usefulness and share with us good practice, materials and ideas that we can then spread across the EU and beyond.





This part of the guide provides messages we collected from different stakeholder groups.

They are not intended to be definitive statements of any one particular group or community, since all groups and communities include people with a range of views and perspectives.

They are presented here because they give valuable insights into issues which health care providers should consider in their vaccine-related conversations and interventions with all parents and carers.

Perspectives

Part I



This part of the action guide is divided into four sections:

- Section 1** A parent (grandparent) and carer perspective
- Section 2** A social marketer, health promoter and media specialist perspective
- Section 3** A vaccination expert and provider (peer) perspective
- Section 4** A so-called “hard-to-reach” population perspective



Section 1

A parent (grandparent) and carer perspective

Summary Messages

- 1.1 Do what you recommend others to do.
- 1.2 Teach us about the risks of non-vaccination.
- 1.3 Tell stories as well as sharing scientific facts.
- 1.4 Take time to listen to our concerns and tell us about possible side effects and risks.
- 1.5 Don't ignore those of us who get immunised – we need reassuring and valuing as champions.
- 1.6 Don't be put off by our efforts to find out more.
- 1.7 Make vaccination easier to access and less stressful.
- 1.8 Redefine success (recognise that some may need more time than others to decide).
- 1.9 Help enhance our vaccination health literacy.

When asked how providers can best build on their trustworthiness and make an effective case for being protected by vaccination, parents, grandparents and carers gave the following advice:

1.1: Do what you recommend others do

We see health care providers not just as sources of information but also as important role models. In order to be convincing, health care providers need themselves to be convinced about the benefits of vaccination. When we see that our nurse, doctor or community health provider neighbours haven't had their kids immunised, it's a problem and massively undermines our confidence.

Some of us also worry that if a health care provider is not protected then they could be a risk to us and our families, as you come into contact with lots of different conditions and diseases in your work. We would be much more reassured if you were doing what you recommend others should do.

1.2: Teach us about the risks of non-vaccination

We recognise that most of us and you, including the young (and not so young) generation of HCPs, have never seen some preventable diseases because they have been prevented! We ask, however, to be told about some of the historical impacts of these diseases. We want facts and figures to show how protection by vaccination has contributed to decreasing the presence of dangerous diseases in our country and the rest of the world over the years. Without this information, decisions about vaccination get focused on vaccine safety and not the risks and effects of the diseases they prevent.

Always discuss honestly the known side effects caused by vaccines, but don't let this be the dominant focus of our

conversations. We need to be **reassured that protecting our children by vaccinating them is the right choice** because the benefits greatly outweigh the risks and in this way we are closing the door to diseases. Moreover, it is important to communicate that the choice not to vaccinate is a risky choice and that not being protected is much more risky than being protected.

1.3: Tell stories as well as sharing scientific facts

For many of us real-life stories are even more important than facts. Point out the severe consequences of the diseases. Show us how the vaccine is protective and preventive. Tell us stories from your own experience about the seriousness of the diseases, or direct us to testimonies from other parents who did not vaccinate and their child became infected with a vaccine-preventable disease.^{viii} Be aware that we want real stories not sensationalism.

Sample Q&A^{ix}- Number of vaccines

Parent: “What are all these vaccines for? Are they really necessary?”

Health care provider: “I know you didn’t get all these vaccines when you were a baby. Neither did I. But we were both at risk of serious diseases like meningitis. Fifty years ago many children died of diseases like diphtheria, tetanus and polio. Nowadays we don’t see these diseases because the vaccines we give protect people. My sister-in-law died of pneumococcal meningitis in her thirties. If she had had the protective vaccine she could be alive today. We’re lucky to be able to easily protect our children from these serious diseases with safe vaccines. Leaving children unprotected is a real and life-long risk.”

^{viii} See Section 8 for links to stories and testimonies.

^{ix} Sample question and answers are presented throughout the guide as an aid to provider-parent conversations.

1.4: Take time to listen to our concerns and tell us about possible side effects and risks

We know that your time is in demand and that making time to talk about getting protected at each visit can be stressful. But when our kids are due to receive protective vaccines, nothing is more important to us than having time to speak with you and know that you are carefully listening to us and assessing our information needs and concerns. We need to know we have your full attention. So please don't make telephone calls or type in your computer when we are looking for reassurance. Maintain eye contact with us and restate our concerns to let us know you have heard them. Your willingness to listen is a key determinant for us in making up our minds about getting our children protected.

Most of us have heard scare stories from friends or the internet about links between measles vaccination, for example, and autism. These stories are often backed up on well-designed anti-vaccination websites, by what are claimed to be 'scientific' facts. We need your help in deciphering fact from fiction. We need your personal and professional opinion that protective vaccines are very safe; and we need your empathetic reassurance that you understand that our infant's health is our top priority, and that it is also your top priority.

Sample Q&A – MMR and autism

Parent: “All those people who say that the MMR vaccine causes autism must be on to something.”

Health care provider: “Autism is such a strong and emotive issue and something we all care about. However, the link made by one doctor to autism has been firmly discredited, and I can show you study after study that demonstrates that there is no link between the MMR vaccine and autism. Unfortunately, once a seed of doubt has been planted it tends to grow, and is fuelled by sensational media and internet coverage that isn’t concerned with the facts. The real issue here is the very real risks from not being protected. I wish the voices of those who have been victims of not getting vaccinated could be heard more loudly and clearly.”

1.5: Don’t ignore those of us who get immunised – we need reassuring and valuing as champions

The reality and good news is that most parents in the EU believe and support immunisation programmes. Many of us, however, decide to immunise without much understanding. A recent study (8) in the Netherlands showed that 81% of Dutch parents made no direct comparative assessment of vaccination before accepting it. While we applaud the fact that these parents are protecting their children, we are concerned that too often acceptance of vaccination means we get less of your attention and time and can be poorly prepared to counter scare stories and misinformation currently being promoted in the media and social media. So even when we do get our children protected, please reassure us, and remind us about the benefits and how we are doing the right thing by protecting them!

1.6: Don't be put off by our efforts to find out more

Many parents today want to work in partnership with you, our family health care providers. When we come to you with a long list of questions or information from the internet or other sources, don't interpret this as a lack of respect for you. Instead, acknowledge that spending time to research protective vaccines means that this is an important topic for us. If you appear offended by questions or if you imply that our questions are uncalled for, dialogue may shut down and trust may be eroded.

1.7: Make vaccination easier and less stressful

Help us make the vaccination visit easier and less stressful for our children. Create a comfortable efficient setting – a medical and clinical environment can be quite daunting for some of us. Talk to us about ways we can hold our babies, distract them and soothe them to reduce stress. If there is room, provide a comfortable space for mothers who may wish to breastfeed after the vaccinations. Consider optional locations for delivering vaccines such as schools, community pharmacies or shopping areas.

1.8: Redefine success (recognise that some may need more time than others to decide)

Success may mean different things with different parents. It may mean that all vaccines are accepted when you recommend them, or that some vaccines are scheduled for another day. If a parent refuses to protect their child

at the time, success may simply mean keeping the door open for future discussions. Some of us find it hard to make a decision and may need time to reflect. So please respect this and keep the door open for follow up with us, even invite us back in. Circumstances may have changed! Whatever you do, please avoid making it a confrontation – we are very unlikely to come back if we feel criticised or challenged in an unhelpful way.

1.9: Help enhance our vaccination health literacy

Please use language we can understand. Try to avoid using too much technical or medical language and if you do, always check with us that we understand what you are talking about: don't assume we know without checking. Providing written information in the form of take-home information sheets, brochures and office posters can be very helpful, especially if understandable, clear language is used and key points illustrated with simple graphics and pictures and links to websites where we can get more information. For those of us with limited literacy skills, use oral communication where possible.

Remember, health literacy is not just about our skills but also means addressing the health-literacy-friendliness of the systems within which we seek care and information. Vaccination schedules are increasingly complex. Even those of us who are motivated can easily forget. Help us to remember appointments with timely reminders and notifications. Some of us really appreciate letter, telephone, mobile phone SMS texts, or email reminders.

Being well informed about the dangers of vaccine

preventable diseases and the importance of protective vaccination empowers (9) us to make the right decisions for ourselves and our families. It also helps us become advocates in our communities for such protective services and delivery systems that help make healthier choices easier.



Section 2

A social marketer, health promoter and media specialist perspective

Summary Messages

- 2.1 Focus on behaviour and its determinants – not just ‘messages’.
- 2.2 Develop accessible, friendly and adapted service settings.
- 2.3 Make the discussion about ‘being protected’ rather than about vaccine safety.
- 2.4 Make those who accept vaccination more visible – build on and reinforce vaccination as a social norm.
- 2.5 Show how refusing vaccination is socially unacceptable.
- 2.6 Ensure any decision to remain unprotected is an active decision.
- 2.7 Use all media to advocate for the need to be protected and to protect.
- 2.8 Actively counter misinformation.

2.1: Focus on behaviour and its determinants – not just ‘messages’

Health information in isolation is rarely enough to achieve sustained health behaviours. The reasons why people decide to get vaccine-protected or remain unprotected can vary between groups and even within similar groups. It is therefore important not to adopt a ‘one-size-fits-all’ approach, but to invest time and effort in understanding and gaining insights into the behaviours (and the various determinants of those behaviours (10)) of the people you are trying to help. Avoid making assumptions about different groups of people and always check out if your understanding of their situation or circumstances is correct by discussing this with them.

Provider-based behavioural interventions for parents can involve simple advice, discussion, negotiation and/or encouragement. On an institutional and community level, providers can advocate for policies and procedures that help make protective vaccination behaviours an easier choice; for example, make settings and delivery systems for vaccination more affordable, accessible and easier to navigate.

2.2: Develop accessible, friendly and adapted service settings

It is particularly important that the settings in which services are provided should avoid being too clinical and medical in feel or tone. Instead, make sure they are friendly, accessible and provide an environment in which different people, parents and children can feel relaxed and comfortable. This may mean adapting service times and locations to different needs and avoiding a ‘one-size-fits-all’ approach. Often services are located in a specific place and then they try to get people to visit them. While this can be done, ways should also be considered of taking services out to where people are, thus minimising the effort and time it takes for people to get a protective vaccine, and making it as easy and simple as possible. Although people don’t generally ‘enjoy’ being vaccinated, removing some of the inconvenience and difficulties in getting protected will go a long way to increasing uptake.

2.3: Make the discussion about ‘being protected’ rather than about vaccine safety.

Framing strategies^x are at the heart of behavioural communication. The language – verbal and visual – in which an issue is expressed, and the terms in which it is presented, can determine how it is perceived and the response to it. This ‘framing’ creates the context within

^x Framing is “selecting some aspects of an issue/topic and making them stand out and dominant in discussions on that issue/topic... in such a way as to promote a particular problem definition, causal interpretation, moral evaluation and/or treatment recommendation.” Adapted from Entman, cited in Chapman (11).

which all immunisation discussions and decisions take place. In a sense, public debates over vaccination represent a battle to frame the issue in the eyes of the public, media and policy-makers. Reframing strategies are key. Much of the success of anti-vaccination, for example, has related to their ability to keep debates focused on vaccine safety as opposed to the serious harm to health which they prevent. Reframing discussions on protection (being protected and protecting) can help put real but small safety risks in perspective.

The use of narratives and visual imaging has been found to be an effective way of reframing messages. Personal stories and narratives can help people relate to the issues more directly. They can help challenge counterarguments, facilitate message recall and comprehension, and provide opportunities for observational learning through identification with characters. People appear more likely to change attitudes towards an issue and disagree less with its points if they can identify with characters in a story, even if they are from a different social class or ethnic group. (12-14).

Sample Q&A – Side effects and long-term effects

Parent: *“I’m worried about the side effects of vaccines. I don’t want my child to get any vaccines today.”*

Health Provider: *“I’ll worry if your child doesn’t get vaccines today, because the diseases can be very dangerous. Measles, pertussis and Hib are still infecting unprotected children in the EU and some such as measles and pertussis are on the rise. Vaccines can protect your child against these diseases. Let’s look at some vaccine information about side effects together.”*

Parent: *“You really don’t know if vaccines cause any long-term effects.”*

Health Provider: *“We have decades of experience with vaccines and there really is no evidence that vaccines cause long-term harm. I understand your concern, but I truly believe that the risk of diseases is far, far greater than any risks posed by vaccines. Vaccines will get your baby off to a great start, ‘protected’ for a long, healthy life.”*

2.4: Make those who accept vaccination more visible – build on and reinforce vaccination as a social norm

It is well established that people are more likely to adopt a behaviour if they understand or perceive that other people like themselves commonly practice the behaviour. This is referred to as ‘social norming’. However, whether a person, parent or their children have been vaccinated or not is not something that is immediately visible to others. Therefore, finding ways to make people aware that others like them have decided to be protected by being immunised is a valuable approach to increasing uptake rates.

Moving protective services into the communities and locations where key audiences live, socialise or work can make them much more visible and help people see that others like themselves are taking up protective immunisation services. Social norming approaches can also harness the influence of those who have been protected through vaccination by being vaccination advocates and champions within their own communities. One potential way to make immunisation more visible would be to build on the fact that we know children like to collect and wear badges. So for example it could be possible during immunisation week to ensure the children who have been protected get a special ‘I’m protected’ badge (or something similar) as a way to make the fact that they have been immunised more visible to other children and parents, and to begin to make the social norm more visible.

2.5: Show how refusing vaccination is socially unacceptable

It can also be useful to look at ways to reinforce that it is socially unacceptable to remain unprotected and increase risks for others. Attention might be focused (e.g., through parent surveys) on whether particular groups (such as teachers, nurses, doctors, social workers, etc.) who come into contact with people should be protected by immunisation as a socially responsible action in their work. Building this issue as an important one can then help individual people and parents reconsider whether they or their children should also be protected. When there is an outbreak, consideration could

be given to unvaccinated children and adults being excluded from schools, child care settings and institutions.

2.6: Ensure any decision to remain unprotected is an active decision

For many the decision not to protect their children is often a passive one, i.e., parents just haven't got around to it or don't consider it particularly important. Moving the situation so that not being protected (remaining unvaccinated) is something that people have to actively sign-up to can be an effective way of getting them to actively (re) consider their decision; e.g., getting parents to sign a form that says that at this moment in time they have specifically decided to not have their children protected. This forces them to actively consider their choice rather than have it as a passive unconsidered decision. Framing this as a decision 'at this moment in time' is also important since this will leave open the potential for those who may decide against protection to revisit this decision in the future (see section 6.5.3-4).

2.7: Use all media to advocate for the need to be protected and to protect

The traditional and new media have been very influential in shaping people's perceptions, behaviours and choices related to protective vaccination. In Ireland and the UK, for example, news coverage of the, in fact false, Wakefield

findings^{xi} drove down the MMR coverage rate considerably. In recent years it has rebalanced and in fact the media have played an important part in getting the message across about the importance of protective vaccines. This has been aided by more consistent messaging from health authorities and the use of ‘data for action’ – using numbers and data to demonstrate the impact of not being protected.

Working with media requires an investment of time and proactive outreach to cultivate good relationships, mutual trust and understanding of respective roles, responsibilities and deadlines. Media work might be done directly or through your institution’s designated media coordinator. Media studies that examine who is reporting on an issue and how it is being discussed and framed in different media channels can help identify the reporters and outlets worth pursuing. Every contact with the media should be viewed as a building block for an on-going relationship (15).

^{xi} The Wakefield MMR articles were published in *The Lancet* in 1998. They pointed to possible associations of MMR vaccine with autism and bowel problems. These findings led to a major reduction in uptake of MMR in the UK and beyond. The findings were subsequently found to be false. Wakefield was struck off the medical register and *The Lancet* withdrew their article. Unfortunately, this took many years and rumours about MMR safety persist to this day.

2.8: Actively counter misinformation

Anti-vaccination forces have effectively used blogs and social media to spread fear and concern about vaccine safety. In many settings, these stories go unanswered. An initiative in the National Health Service (NHS-UK) vaccine information centre has shown the importance of actively countering negative anti-vaccine stories. Every time there is a potentially influential news article (positive or negative) about vaccination, the NHS information service posts it on its website and informs the public with evidence-based comments and makes sure that false information is not left unchallenged. The London School of Hygiene and Tropical Medicine (LSHTM) vaccine confidence website (see section 8.2) also provides regular updates on relevant vaccine ‘confidence’ related news (16).

Box 1: Advice to parents on evaluating internet sources of immunisation information

Check the website's ownership, purpose, authors, and organizations that support it. If the website address ends in .edu, it is a school, college or university. Some other common endings are:

- .gov (government);
- .org (non-profit organizations);
- .int (international organizations); and
- .com (mostly commercial).

Check that information is based on sound scientific study. A trustworthy website will clearly state the name of an author whose work appears on the site and will provide information based on sound scientific research, not on opinion. References and links to formal academic publications should be provided to support statements.

Questions to consider:

- Does the website claim seem too good- or too bad- to be true? If so, it likely is.
- Are the claims based on the idea of a conspiracy? Does the website say it has discovered "the hidden truth" about vaccines? If so, avoid it.
- Is the information based on emotion rather than scientific fact?

Discuss your findings with your health care provider and ask them for their views.



Section 3

A vaccination expert and provider (peer) perspective

Summary Messages

- 3.1 Keep your immunisation knowledge current.
- 3.2 Strengthen your communication skills.
- 3.3 Use the team and other settings to provide information and address concerns.
- 3.4 Maintain your skills to ensure safe vaccine administration.
- 3.5 Guide parents to reliable information sources.

3.1: Keep your immunisation knowledge current

Studies show that health care providers generally have confidence in vaccines but are often unprepared to answer the detailed questions patients may pose about vaccine safety, ingredients, reported side effects, potential contraindications, etc. (see related questions and answers in section 6). To address this, health care providers need to seek out, or regularly receive from their health authorities, independent and evidence-based information from trustworthy sources. A regular update of vaccine-related information should be a routine part of every provider's continuing medical education. Associations and academic centres can help by building relevant updates into their course offerings. It is also important to actively interact with agencies responsible for the scientific evaluation of medicines developed by pharmaceutical companies to ensure that this information is rigorous, available, accessible and current (17). Providers must critically appraise promotional materials received from pharmaceutical company representatives.

3.2: Strengthen your communication skills

The advice provided in this guide identifies a wide variety of ways you can strengthen your communication skills. Underpinning most of this advice is the need for conversations between you and parents that sensitively address concerns and patiently answer their questions. Many have found the logical CASE approach to conversation useful (see Box 2).

Box 2: The CASE approach

Adapted from Allison Singer, Autism Science Foundation – see www.autismsciencefoundation.org

- Corroborate:** Acknowledge the patient’s concern and find some point on which you can agree. This sets the right tone.
- About Me:** Describe what you have done to build your knowledge base and expertise.
- Science:** Describe what the science says.
- Explain/Advise:** Give advice to patient, based on the science.

Applying the CASE approach

Parent: *“I want to spread out the vaccinations so they won’t overwhelm my child’s immune system.”*

Provider:

- **Corroborate:**
“Children today certainly get more vaccinations than children did years ago.”
- **About Me:**
“Our practice follows the [national] schedule because it is carefully designed to protect children at the time they are most vulnerable to disease. I recently returned from a meeting, or I served on a committee that reviewed the schedule...”
- **Science:**
“Although children get more vaccinations today, they actually receive fewer foreign proteins than when

they got fewer vaccinations, because technology has enabled us to make vaccines that have only the part of the cell that induces immune response. Plus, the immunological challenge from a vaccine is nothing compared to what kids fight off every day. An ear infection is a bigger immunological challenge.”

- **Explain:**

“We want all the children in our Practice to be immunised so that they have the greatest chance for a long, healthy life.”

You need insight into parents’ understanding of vaccines and the factors that shape their perceptions, behaviours and choices. Based on this knowledge you need to know how to transmit information and generate trust and respect; how to explain things clearly, give simple answers and listen to the specific needs. Remember, not all parents want the same level of medical or scientific information about vaccines. By assessing the level of information that a particular parent wants (see Box 3), you can communicate and use your time more effectively.

Box 3: Addressing the hesitant, unconcerned, resistant and poorly reached: Discussion tips

[Adapted from www.wdghu.org, Canada, 2005 (18)]

1. Listen, Evaluate, Categorise

- Determine specific concerns of parents so you can provide more effective information, reasons, and arguments.
- Dedicate enough time to make the discussion effective.
- Assess if the parent is truly seeking advice. Avoid wasted time and effort with those who are not.

Category	Characteristics	Chance of positive outcome (immunisation)
THE HESITANT		
Uninformed	Told by others not to immunise, but seek information to counter argument.	High.
Misinformed	Gathered info from media; haven't heard the other side of the story.	May slowly change their position and frequently consent to immunisation at a later date.
Well-read and open-minded	Aware of anti-immunisation info and have done reading on the subject. Need help prioritising each argument and pointing out false logic.	Need to be prepared for discussion with client, but often ultimately agree to immunise. May start with certain vaccines and agree to add others over time.

Category	Characteristics	Chance of positive outcome (immunisation)
THE UNCONCERNED		
Un-informed	Simply unaware of dangers of vaccine preventable diseases.	High.
Informed but self-serving	Concerned about safety of vaccines. Aware of herd immunity and assume that will protect their child.	Need to be prepared for discussion with parent, but often ultimately agree to immunise. May start with certain vaccines and agree to add others over time.
ACTIVE RESISTERS		
Convinced and content	Convinced that immunisation is bad and content with the decision not to immunise. In your office because someone has “badgered” them to discuss it with their physician.	Success is unusual, but discussion may lead them to re-examine their position in the future. Extensive discussion is seldom productive.
Committed and missionary	Staunch anti-immunisation position. At your office to convince you to stop immunisation of all patients.	Patients in this category have strongly held beliefs and do not appreciate the value of immunisation; extensive discussion is non-productive.

Category	Characteristics	Chance of positive outcome (immunisation)
POORLY REACHED		
Socially excluded	A wide variety of social determinants shape people's perceptions, choices and behaviours related to vaccination.	Social and cultural sensitivity, engagement strategies (from planning to implementation and evaluation); community intermediaries (e.g., Roma Health Mediators) can help.
Working and time pressured	Would like to get vaccinated but opening hours, locations, etc inconvenient	Extended hours and/or alternative locations can help address this group.

2. Recognise Legitimate Concerns

- Acknowledge that adverse events can be associated with vaccines and that concerns are legitimate.
- Emphasise that most adverse events are mild and self-limiting (e.g., soreness at injection site). Discuss the less common, more severe adverse events and stress that most have no lasting effect (e.g., febrile seizure).

Do not ignore the rare, severe adverse events such as anaphylaxis.

3. Provide Context

- Provide parents with the comparative risks associated with the vaccine and with the disease.
- Discuss the likelihood of becoming infected in the absence of immunisation.

- Review what has happened in countries where immunisation rates have fallen and vaccine-preventable diseases have re-emerged.

4. Refute Misinformation

- Know the claims made by anti-immunisation groups. Be able to clarify fallacies.
- Visit anti-immunisation websites and examine the tactics they use.
- Research parents' specific issues. Provide information from reputable sources.

5. Provide Valid Information

- Respond to incorrect information and provide reliable data on elimination of disease, decreased mortality, and the effects of an interrupted vaccine programme. Don't be defensive.
- Offer parents a public health handout that lists valid references and internet sites.

6. Educate About Potential Consequences

- Ensure parents understand the consequences of contracting the disease and related risks. They are often concerned about vaccination risks and ignore the risk of not immunising.

7. Make a Clear Recommendation

- Make clear your opinion and any recommendations.

3.3: Use the team and other settings to provide information and address concerns

Time is the most common obstacle identified by providers to carrying out conversations with their patients. Many primary care practices and surgeries address this challenge by engaging, educating and training a broad range of primary care providers in running special vaccination information sessions or groups. Some surgeries and clinics have designated vaccine information specialists and/or make information (and links to reliable websites) available in waiting rooms with information brochures and posters. Some provide information evenings for parents or organise sessions for informing future parents when they visit midwives and obstetricians.

3.4: Maintain your skills and ensure safe vaccine administration

People do not perceive vaccines in the same way that they view other pharmaceutical products. Unlike medications which tend to be categorised and scrutinised in a wide variety of disease- or organ-specific categories (e.g., heart, kidney, skin, etc.), all vaccines tend to be placed in a common 'safety' basket. If anything goes wrong with any vaccine, all vaccines are looked at with more suspicion. Vaccine safety is therefore key. We must all maintain our vaccination knowledge and skills at a high level. A variety of skills checklists are available to help health care providers self-assess their competencies and seek training for weak areas (see Boxes 4 and 5).

Box 4: Skills checklist for protective immunization: Health care provider self-assessment

(Adapted by the European Centre for Disease Control (ECDC) from the original produced by the California Department of Health Services – Immunization Branch. You are welcome to use our materials. They are considered public domain. Feel free to remove our California logos/information and replace it with your own. Please add a credit: “Reproduced with permission from the California Department of Public Health, Immunization Branch“. If you wish to make any other changes to the content of the document, please do not include the credit to us.

www.cdph.ca.gov/programs/immunize/Pages/Default.aspx

The Skills Checklist is a self-assessment tool for health care providers who administer immunisations. To complete it, review the competency areas below and the clinical skills, techniques and procedures outlined for each of them. Score yourself in the Self-Assessment column. If you check ‘Need to improve’, you indicate further study, practice or change is needed. When you check ‘Meets or exceeds’, you indicate you believe you are performing at the expected level of competence, or higher.

Competency	Clinical Skills, Techniques, and Procedures	Self-Assessment	
		Need to improve	Meets or exceeds
A. Patient/Parent Education	1. Welcomes patient/family, establishes rapport, answers any questions, and explains where more information can be obtained.		
	2. Explains what vaccines will be given and which type(s) of injection will be done.		
	3. Accommodates language or literacy barriers and special needs of patient/parents to help make them feel comfortable and informed about the procedure.		

Competency	Clinical Skills, Techniques, and Procedures	Self-Assessment	
		Need to improve	Meets or exceeds
	<ol style="list-style-type: none"> 4. Verifies patient/parents have received information for indicated vaccines and had time to read it and ask questions. 5. Screens for contraindications. 6. Reviews comfort measures and after care instructions with patient/parents, inviting questions. 		
B. Medical Protocols	<ol style="list-style-type: none"> 1. Identifies the location of the medical protocols (i.e., immunisation protocol, emergency protocol, reference material). 2. Identifies the location of the epinephrine, its administration technique, and clinical situations where its use would be indicated. 3. Maintains up-to-date CPR certification. 4. Understands the need to report any needle stick injury and to maintain a sharps injury log. 		
C. Vaccine Handling	<ol style="list-style-type: none"> 1. Checks vial expiration date. Double-checks vial label and contents prior to drawing up. 2. Maintains aseptic technique throughout. 3. Selects the correct needle size. 1–1½" for IM (DTaP, Td, Hib, HepA, HepB, Pneumo Conj., Flu); ⅝" for SC (MMR, Var); IPV and Pneumo Poly depends on route to be used. 		

Competency	Clinical Skills, Techniques, and Procedures	Self-Assessment	
		Need to improve	Meets or exceeds
	4. Shakes vaccine vial and/or reconstitutes and mixes using the diluent supplied. Inverts vial and draws up correct dose of vaccine. Rechecks vial label.		
	5. Labels each filled syringe or uses labelled tray to keep them identified.		
	6. Demonstrates knowledge of proper vaccine handling, e.g., protects MMR from light, logs refrigerator temperature.		
D. Administering Vaccines	1. Rechecks the physician's order or instructions against prepared syringes.		
	2. Washes hands and if office policy puts on disposable gloves.		
	3. Demonstrates knowledge of the appropriate route for each vaccine. (IM for DTaP, Td, Hib, HepA, HepB, Pneumo Conj, Flu; SC for MMR, Var; either SC or IM for IPV and Pneumo Poly).		
	4. Positions patient and/or restrains the child with parent's help; locates anatomic landmarks specific for IM or SC.		

Competency	Clinical Skills, Techniques, and Procedures	Self-Assessment	
		Need to improve	Meets or exceeds
	5. Checks skin at injection site. Clean skin does NOT require cleansing. Visibly dirty skin should only be washed with soap and water. If alcohol and other disinfecting agents are used, skin must be allowed to dry as these could inactivate live vaccines.		
	6. Controls the limb with the non-dominant hand; holds the needle an inch from the skin and inserts it quickly at the appropriate angle (45° for SC or 90° for IM).		
	7. Injects vaccine using steady pressure; withdraws needle at angle of insertion.		
	8. Applies gentle pressure to injection site for several seconds with dry cotton.		
	9. Properly disposes of needle and syringe in sharps container. Properly disposes of live vaccine vial.		
	10. Encourages comfort measures before, during and after the procedure.		
	11. Observes patient for any adverse reaction and administers appropriate therapy if adverse effect occurs.		

Competency	Clinical Skills, Techniques, and Procedures	Self-Assessment	
		Need to improve	Meets or exceeds
E. Records Procedures	1. Fully documents each immunisation in patient's chart: date, lot number, manufacturer, site, name/initials.		
	2. Reports any adverse effect to proper authorities.		
	3. If applicable, demonstrates ability to use registry or computer to call us a patient's record, assess what is due today, and update computer immunisation history.		
	4. Asks for and updates patient's record of immunisations and reminds them to bring it to each visit.		

Some suggestions for action to improve skills include:

- a. Watch video on immunization techniques.
- b. Review office protocols.
- c. Review manuals, textbooks, wall charts or other guides.
- d. Review package inserts.
- e. Review vaccine handling guidelines or video.
- f. Observe other staff with patients.
- g. Practice injections.
- h. Read Vaccine Information Statements.
- i. Be mentored by someone who has these skills.
- j. Role play with other staff – interactions with parents and patients, including age-appropriate comfort measures.
- k. Attend a skills training or other courses or training.
- l. Attend health care customer satisfaction or cultural competency training.
- m. Renew CPR certification.

Other: _____

Box 5: Administering Vaccines

[Acquired from www.immunize.org/catg.d/p3085.pdf on August 2012.

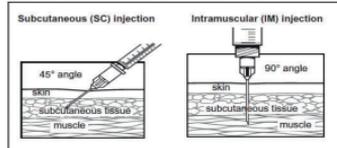
We thank the Immunization Action Coalition.]

Administering Vaccines: Dose, Route, Site, and Needle Size

Vaccines	Dose	Route
Diphtheria, Tetanus, Pertussis (DTaP, DT, Tdap, Td)	0.5 mL	IM
<i>Haemophilus influenzae</i> type b (Hib)	0.5 mL	IM
Hepatitis A (HepA)	≤18 yrs: 0.5 mL ≥19 yrs: 1.0 mL	IM
Hepatitis B (HepB)	≤19 yrs: 0.5 mL* ≥20 yrs: 1.0 mL <i>*Persons 11–15 yrs may be given Recombivax HB® (Merck) 1.0 mL adult formulation on a 2-dose schedule.</i>	IM
Human papillomavirus (HPV)	0.5 mL	IM
Influenza, live attenuated (LAIV)	0.2 mL	Intranasal spray
Influenza, trivalent inactivated (TIV)	6–35 mos: 0.25 mL ≥3 yrs: 0.5 mL	IM
Measles, mumps, rubella (MMR)	0.5 mL	SC
Meningococcal – conjugate (MCV)	0.5 mL	IM
Meningococcal – polysaccharide (MPSV)	0.5 mL	SC
Pneumococcal conjugate (PCV)	0.5 mL	IM
Pneumococcal polysaccharide (PPSV)	0.5 mL	IM or SC
Polio, inactivated (IPV)	0.5 mL	IM or SC
Rotavirus (RV)	2.0 mL	Oral
Varicella (Var)	0.5 mL	SC
Zoster (Zos)	0.65 mL	SC
Combination Vaccines		
DTaP+HepB+IPV (Pediaris®) DTaP+Hib+IPV (Pentacel®) DTaP+Hib (Trihibit®) DTaP+IPV (Kinrix®) Hib+HepB (Comvax®)	0.5 mL	IM
MMR+Var (ProQuad®)	≤12 yrs: 0.5 mL	SC
HepA+HepB (Twinrix®)	≥18 yrs: 1.0 mL	IM

Injection Site and Needle Size		
Subcutaneous (SC) injection		
Use a 23–25 gauge needle. Choose the injection site that is appropriate to the person's age and body mass.		
Age	Needle Length	Injection Site
Infants (1–12 mos)	5/8"	Fatty tissue over anterolateral thigh muscle
Children 12 mos or older, adolescents, and adults	5/8"	Fatty tissue over anterolateral thigh muscle or fatty tissue over triceps
Intramuscular (IM) injection		
Use a 22–25 gauge needle. Choose the injection site and needle length appropriate to the person's age and body mass.		
Age	Needle Length	Injection Site
Newborns (1 st 28 days)	5/8"	Anterolateral thigh muscle
Infants (1–12 mos)	1"	Anterolateral thigh muscle
Toddlers (1–2 yrs)	1–1¼" 5/8–1½"	Anterolateral thigh muscle or deltoid muscle of arm
Children & teens (3–18 years)	5/8–1½" 1"–1¼"	Deltoid muscle of arm or anterolateral thigh muscle
Adults 19 yrs or older	5/8–1½"	Deltoid muscle of arm
Male or female less than 130 lbs	5/8–1½"	Deltoid muscle of arm
Female 130–200 lbs Male 130–260 lbs	1–1½"	Deltoid muscle of arm
Female 200+ lbs Male 260+ lbs	1½"	Deltoid muscle of arm

*A 5/8" needle may be used *only* if the skin is stretched tight, subcutaneous tissue is not bunched, and injection is made at a 90-degree angle.



Please note: Always refer to the package insert included with each biologic for complete vaccine administration information. CDC's Advisory Committee on Immunization Practices (ACIP) recommendations for the particular vaccine should be reviewed as well.

Technical content reviewed by the Centers for Disease Control and Prevention, February 2009.

www.immunize.org/catg.d/p3085.pdf • Item #P3085 (2/09)

Immunization Action Coalition • 1573 Selby Ave. • St. Paul, MN 55104 • (651) 647-9009 • www.immunize.org • www.vaccineinformation.org

3.5: Guide patients to reliable information sources

Parents have to know where they can find reliable information: otherwise, when they are looking for information on the internet they will more frequently be directed to anti-vaccination websites than to websites with objective information about vaccinations (Liesbeth Mollema, 2012, personal communication).

A photograph showing a blurred crowd of people walking in a brightly lit indoor space, possibly a transit station or a public area. The motion blur suggests a fast-paced, busy environment. The people are wearing various casual clothing, including jackets and trousers. The background is bright and out of focus.

Section 4

A so-called 'hard-to-reach' population perspective

Summary Messages

- 4.1 Introduction.
- 4.2 Advice from the socially disadvantaged group perspective.
- 4.3 Advice from an anthroposophist perspective.

4.1: Introduction

For the purposes of this guide, so-called ‘hard-to-reach’ populations (see reframing discussion 4.2.2 below) refer to groups of people who are unprotected or under-protected because of social and/or geographical isolation and exclusion or those who resist vaccination due to religious and philosophical beliefs. These can include some from the following groups: Roma communities; Traveller communities; anthroposophists; Ultra-orthodox Jewish communities or Christian Reformed Church; as well as other reformists and radical groups. These are described briefly below.

Roma communities

The Roma form a significant ethnic group living in Europe. The current estimate of the total population of Roma living in the EU is 6–8 million. Accurate estimates are difficult due to mobility and fear of registering as Roma due to stigmatisation. Roma reported the highest overall levels of discrimination of all groups surveyed (ranging up to 64% of survey population) in the fifth European Union Minorities and Discrimination Survey 2010 (19). There is great heterogeneity within and between Roma groups and subgroups. In some countries and communities Roma are well integrated, but in many others they suffer social isolation and their health and relationship with health systems are determined to a large extent by their living conditions and other social factors.

A wide range of obstacles (and opportunities) to health promotion and disease prevention amongst Roma have been reported (see Box 6). Roma comprise many different subgroups with diverse culture and traditions and all groups have their own individual beliefs and customs (20). Countries with the highest percentage of Roma people in the EU include Bulgaria, Romania, Czech Republic, Slovakia, Hungary, Spain and Greece.

Box 6: Obstacles (and opportunities) to health promotion and prevention for Roma

Those Roma who live in socially disadvantaged contexts experience, as other groups in the same situation, socially determined barriers to access to health systems and even more to prevention services. There are many causes for these obstacles (which also represent opportunities for corrective action).

Structural/environmental factors include poverty, high unemployment, low education, inadequate (knowledge and application of) rights protection, weak or complex registration systems (e.g., births, health insurance), poor living conditions including inadequate water and sanitation systems, housing, roads (with transportation challenges related to care), poor access to healthy food supplies, primary and secondary health services; and lack of appropriate or weak and inconsistent implementation of legislation related to mandatory vaccination, surveillance and reporting systems (e.g., absence of disaggregated social and economic data).

Perceptual/behavioural factors include: negative attitudes and mistrust (bi-directional) between the Roma communities and public institutions; negative perceptions of and attitudes towards Roma by health-care staff; low health literacy; poor access to health information; poor or different understanding of different infectious disease risks; difficulty in navigating health and social care systems; poor communication skills of health care providers and lack of target-specific information materials in health facilities and by health providers; as well as stigma and discrimination (21).

Traveller communities

Travellers are a nomadic people of Irish origin forming a minority living mostly in Ireland and Great Britain. Population estimates vary widely from 82,000–300,000 (20). UK studies show that access to health services is difficult because of Travellers' lack of permanent addresses.

Anthroposophy

Anthroposophy is a spiritual philosophy based on the teachings of Austrian-born Rudolf Steiner (1861–1925), who described it as “a way of knowledge – a cognitive path – that leads the spiritual in the human being to the spiritual in the universe” (20). Steiner considered disease and healing processes (such as measles in early childhood) as opportunities for the development of the physical and the

etheric body. As of 2011 there were 998 Steiner schools worldwide (also known as Waldorf schools) which follow anthroposophic concepts of education, with approximately 700 in Europe. There is a current debate on measles vaccination amongst anthroposophic physicians in some countries, e.g., Germany (20).

Some people within particular religious communities

Ultra-orthodox Jewish communities in Israel, the UK, France and Belgium and other countries, can include small subgroups that evade services provided by governmental agencies and health authorities. Members of the Christian Reformed Church in the Netherlands refrain from vaccination on religious grounds (22).

Other reformist and/or radical resistant groups

In addition to some of the socially excluded and religious groups resistant to vaccination described above, Hobson-West (23) identifies a variety of reformist and/or radical groups (often well represented on the internet) who oppose vaccination. The reformists tend to be led by parents who have personal experience with children whom they believe have been seriously injured following vaccination. These groups are not completely against vaccination per se but want better recognition of side effects. Radical groups, on the other hand, are actively critical of vaccination and have dedicated websites and blogs. They associate vaccination with untrustworthy science linked with unethical behaviours, animal testing, 'big pharma', etc. The 'deep/dark green' resisters, are more interested in and promote alternative medicines and more

organic, natural approaches to disease prevention and treatment.

4.2: Advice from the socially disadvantaged group perspective

Summary messages

- 4.2.1 Know more about us.
- 4.2.2 Reframe ‘hard-to-reach’ as ‘poorly-reached’ system failures.
- 4.2.3 View immunisation as one part of larger health challenges.
- 4.2.4 Integrate us into mainstream programmes.
- 4.2.5 Involve us in all stages of programmes aimed at enhancing our inclusion and health.
- 4.2.6 Adapt governance and health systems to be more inclusive.
- 4.2.7 Health mediators and other community health workers are critically important resources – they need to be supported.
- 4.2.8 Be accessible and respectful.
- 4.2.9 Beware of incentives that could be viewed as bribes for compliance.

4.2.1: Know more about us^{xii}

Health care providers who work with us should have background knowledge of our culture and the perceptions we have with regards to health; information regarding

^{xii} The voices and messages expressed in the text are based in some instances on translations of respondents’ own language.

the health status of our people; insight into the internal diversity of the our communities; and awareness of the strengths and weaknesses of prior intervention experiences (e.g., see Box 7 with information on Roma attitudes, beliefs and values).

Box 7: Roma health – attitudes, beliefs and values in brief^{xiii}

Our perception of health:

For many of us, health is not perceived as a top priority. Housing, finances and/or employment all come ahead of health in our list of priority needs. When it comes to health, many of us understand health as the absence of disease and disease as an incapacitating phenomenon linked to death. Therefore, for us health only becomes a concern in the presence of very dramatic symptoms and incapacitating consequences. Once we or a member of our family perceives the presence of disease, action taken must be immediate and definitive. If symptoms disappear under treatment, all other therapeutic guidelines are generally ignored because from our perspective the disease has vanished (24).

^{xiii} Some terms such as “For many of us, health is not perceived as a top priority” may not be reflective of all the community.

Cultural identity:

This is omnipresent in our community and is the source of great pride and community self-esteem. Community support for us is closely linked with a feeling of cultural identity. This is why so few of our elderly or those with a physical disability or mental disease are institutionalised. This is also why community- or family-based approaches, instead of individual approaches, work better with us.

Health protective norms:

Certain traditional norms, such as a prohibition on the use of tobacco and alcohol in the case of women or the limiting of sexual relations to marriage (especially with regard to women), serve as health protection factors for us. Traditionally, despite difficult environmental conditions we Roma adhere to a number of hygiene practices, such as the widespread use of bleach as a disinfectant, clear differentiation of unclean objects or areas from clean ones, etc.

Social organization:

For us this is based on the extended family, the nucleus around which social and personal relations develop. That is why when one of us falls ill, the entire family and not just close family members accompanies us to obtain services. It is also why the relationships established are not usually between the individual and the health care system but rather between the individual who is ill, the extended family and the health care system. Please see this as an opportunity not as a disruptive force.

How we judge quality:

For many of us, quality of treatment is mostly based on the length of the visit, whether we think we are treated respectfully as persons, perceived empathy, non-verbal communication, etc. Our fears ('frica') around vaccination, for example, often relate to our understanding of past history. In Romania, for example, we heard there was the spread of HIV in the late 1980s from the use of non-sterilised, reused needles. That is why we like to go and watch how our children get their vaccinations. We, like other concerned parents in the population, want to see that single-use syringes and needles are used and that fresh vials of vaccine are opened just for our children.

Mutual distrust:

Mutual prejudice between health care providers and ourselves often leads to a relationship based on defensiveness and mistrust. These prejudices, charged with a powerful emotional component, are often based on negative individual experiences which tend to fuel prejudice while positive experiences, perceived as exceptions to the rule, do not have a counterbalancing effect. This is a challenge we both need to work on to solve.^{xiv}

^{xiv} Some of the phrases used such as “mutual distrust” and “mutual prejudice” fail to acknowledge the power relations and the statutory duty of a service provider and their mandates to treat all people equally. The real and actual use of immunisation services should result in the right to healthcare for mothers and children (Maria Daly and Siobhan Curran, Pavee Point Traveller and Roma Centre, Dublin, 2012, personal communication).

4.2.2: Reframe 'hard-to-reach' as mainly 'poorly reached' system failures

Most of the time people label us as 'hard-to-reach' based on their own perceptions of our individual or community characteristics. Often these opinions are shaped by negative stereotypes and discriminatory attitudes towards our peoples. Too often, health care providers are unable to differentiate group-specific cultural aspects and others which are more related to the socio-economic culture of marginalisation in which our families find themselves. Responsibility for vaccination failures are often projected onto individuals and communities and the social determinants of these behaviours are ignored (see Table 1). Addressing obstacles to our protective vaccination uptake requires attention not only to our behaviours but to broader system issues as well, including education, transport, registration and service delivery policies.

We aren't just hard-to-reach – we are more often poorly reached or under-served!

In Ireland, for example, we who are Travellers, living in halting sites, have difficulties due to low literacy (we get invites but cannot read them), mobility (we move around a lot and cannot register with GPs due to lack of mailing addresses) and sometimes the postmen do not deliver our letters because of their attitudes towards and fear of us (Suzanne Cotter, 2012, personal communication).

Table 1: Determinants of socially disadvantaged populations' exposure, vulnerability, access to and consequences of care related to communicable diseases (21)

<p>Increased exposure</p>	<p><i>Some socially disadvantaged groups are more likely to be exposed to communicable disease because they have:</i></p> <ul style="list-style-type: none"> less access to improved water sources; inadequate and over-crowded living conditions with poorly ventilated housing; poor herd immunity for vaccine-preventable diseases in their immediate community; more exposure to sick family members or other contacts who have delayed treatment.
<p>Increased vulnerability</p>	<p><i>Once exposed to an infectious agent, some socially disadvantaged groups are more likely to become infected because of:</i></p> <ul style="list-style-type: none"> underlying malnutrition (micronutrient deficiencies, underweight, and in some contexts, overweight); underlying illness; unvaccinated or incomplete vaccination; less access to other (non-vaccine) preventive measures.
<p>Poorer access to quality services</p>	<p><i>Once they are sick, socially disadvantaged groups generally have poorer access to quality health care services because of:</i></p> <ul style="list-style-type: none"> discrimination or culturally incompetent care; being more likely to avoid seeking care due to having experienced or heard about discrimination in health care settings; living far from a health centre; the lack of health insurance or other requirements for accessing care;

	<p>cost;*</p> <p>not being able to purchase medicines prescribed;</p> <p>problems in adhering to certain treatments, such as those for particularly stigmatised or expensive-to-treat illnesses; and,</p> <p>misunderstanding of treatment prescribed due to low education/literacy levels.</p>
<p>Worse consequences of contact with health system</p>	<p><i>Utilising health services may entail worse consequences for socially disadvantaged groups because:</i></p> <p>Catastrophic expenses can lead to further impoverishment and decreased demand for health care in the future.</p>

* Cost factors are reduced significantly where there is equitable provision of immunisation to all children by all providers (Maria Daly and Siobhan Curran, Pavee Point Traveller and Roma Centre, Dublin, 2012, personal communication).

4.2.3: View immunisation as one part of larger health challenges

We think that a comprehensive approach to health should be taken, rather than specific actions for each health matter. It is important to take into account that vaccination is only one of the actions that can contribute to better health, but no more important than other prevention and health promotion actions. Immunisation programmes need to be placed in a larger context and moved from isolated projects to being part of broader initiatives that address health inequities, acknowledge social

determinants of health^{xv} and support sustained inclusion solutions: e.g., resource building – HCP training; service delivery – adjusting opening hours, having mobile units; and financing – reducing the burden of out-of-pocket payments. On the positive side, the skills and capacities required to support increased immunisation are the same needed to address many of the broader challenges our populations face.

4.2.4: Integrate us into mainstream programmes

Supplemental protective vaccination programmes/days may be needed from time to time, but our preference is for them to be integrated into existing systems in order to develop the relationships, knowledge, navigational skills (health literacy) and trust needed to sustain change and maintain engagement with protective vaccination programmes. The information we need most of the time is the same as the rest of the population. Universal information and education materials approaches should be developed for the entire population and then adapted, as required, to create culturally appropriate and inclusive services and supports that address specific groups with their own characteristics. Adaptation should include asking us about our needs and perceptions.

^{xv} Belonging to a minority ethnic group has a bearing on the emergence of specific health inequalities. These inequalities are not only rooted in socio-economic variables but are also the product of barriers blocking access to healthcare services and ineffective use of such services due to poor adaptation or even discrimination. The processes of exclusion and social marginalisation limit people's access to healthcare services and the use they make of them (24).

4.2.5: Involve us in all stages of programmes aimed at enhancing our inclusion and health

We know that our engagement with any development initiative is a crucial factor. Enhancing protective immunisation uptake, therefore, requires our proactive involvement in participatory research, priority setting, policy development and implementation. In particular, peer-to-peer activities with the enhanced use of local social workers, teachers, assistants and mediators have been shown to be helpful.

Ensure our participation in cross-sectoral work and multidisciplinary teams, local research, training, intercultural mediation and peer education, adaptation of teaching materials, information and awareness campaigns.

4.2.6: Adapt governance and health systems to be more inclusive

Too often, even though we bring our children to immunisation providers, vaccines cannot be administered because of ‘system’ requirements beyond our and our providers’ control.^{xvi} We are refused access to GP and primary care services, for example, on the basis that we do not have a valid medical card, and/or are not in receipt of social welfare payments. When access is available, scheduling needs to be flexible to give us time for communication exchanges that acknowledge and

^{xvi} New legislation such as The Habitual Residency Act in Ireland has contributed to difficulties in obtaining decisions on Social Welfare entitlements which directly impact access to medical services for children and their families (Maria Daly and Siobhan Curran, Pavee Point Traveller and Roma Centre, Dublin, 2012, personal communication).

strengthen our health literacy. Moreover, service systems can be: enhanced with home visits by doctors, use of mobile teams, community nurses; use of school settings as platforms for health promotion; strengthened involvement of local NGOs, including faith-based workers and other actors (related to alert systems, information services, health education and promotion) in the vaccination process.

We know that the interventions that have been most effective in countries and localities are those that approach problems with cross-government (inter-sectoral) coordinating approaches to socially excluded population health policy development and implementation: e.g., a Government Council for Roma Minority Affairs, State Council for Roma Health, or locally based integrated medical and social care centres which can perform information and monitoring tasks. Such approaches challenge discrimination and practices that exclude Roma and Traveller Communities.

4.2.7: Health mediators and other community health workers are a critically important resource for us – they need to be supported

Roma health mediators, for example, have helped us increase vaccination rates, obtain identification and insurance documents and provided health education to our children and ourselves. They listen to our concerns and undertake follow-up so that we don't have to worry about having to deal with health issues alone. They have in many

instances become our spokespeople with health systems. They need to be integrated into mainstream systems, receive appropriate training, recognition and salaries. Putting all the responsibility for intervention on their shoulders, however, could be a danger, as we worry that it can lead to disinterest on the part of others (the rest of the health system professionals, in this case). Ultimately our main goal is the normalisation and complete integration of our population groups into the mainstream systems.

We have also found that systems that support increasing local capacity to communicate effectively and provide materials to assist in communication have also been effective. Pavee Point – a Traveller NGO (with government support) in Ireland – has trained community health care providers, who are (usually) women from the community, who do a lot of peer-to-peer education and encouragement on health-related matters.^{xvii}

4.2.8: Be accessible and respectful

As noted above, for us human warmth in the treatment process, perceived empathy and the feeling of being listened to and understood are among the most important criteria in assessing the quality of health care services. It is, therefore, essential that you pay particular attention to these aspects, especially when a relationship is first being established with the different members of socially isolated communities. Always remember that different does not mean problematic or vaccine-refusing. Be prepared to invest time in building

^{xvii} PHC Projects for Travellers are active in 30 areas across the country and do awareness raising, information dissemination, and vaccination promotion (see <http://paveepoint.ie>).

relationships. Unfortunately we have too often found that health care services and providers have great difficulties in employing flexibility in the face of differences. The lack of tailored protocols is one of those difficulties. As long as procedural protocols are lacking, many professionals claim that they are complying with general protocols (“I’m just doing what I was told to do”), while care adapted to the members of minority groups will continue to be perceived as something voluntary, reserved only for ‘sensitive’ service providers. We know that providing training to staff and service providers on Traveller and Roma culture and health needs can help make our interactions more effective and fulfilling.

4.2.9: Beware of incentives that could be viewed as bribes for compliance

Incentives for protection or disincentives for non-protection can play a role in influencing behaviours. But there is a fine balance and it could go horribly wrong if you are seen to be ‘buying’ practices. Recognise that money is only one type of incentive or disincentive, so consider whether there are others (i.e., not just financial) that may be valued by our community.

4.3: Advice from an anthroposophist perspective

Summary messages^{xviii}

4.3.1 Understand us better.

4.3.2 Listen to our concerns – give us time.

4.3.1: Understand us better

We are concerned about the fact that modern society is so fast and parents have increasingly less time for their children and that illness and infirmities are perceived as problems to eliminate. For us anthroposophists, paediatric illnesses are valued positively because we understand them to be a part of the physical development of our children. We see them as ‘helpers’, especially, in our children’s early development.

4.3.2: Listen to our concerns – give us time

When we take a decision about vaccination we like time to reflect and consider options. All of us can make our choices about vaccination. We like going to our anthroposophical surgeries because they spend more time with us. They are more willing to adapt a national programme to meet our needs and concerns. They give attention to each individual child and do what is best for them.

^{xviii} Many thanks to Nelly Fournet and Liesbeth Mollema for sharing work in progress in this area.



This part of the action guide:

Here the aim is to give you, as health care providers, support in your conversations about vaccination with families, community leaders and media.

It has four sections. Section 5 presents information tables and graphics to help you make the case for vaccination. Section 6 includes some examples of patient information sheets that can reinforce the messages you deliver. It also includes some forms to help document refusal to vaccinate. Section 7 provides some ideas to help you answer patients' most common questions. Section 8 provides links to stories and a list of useful websites that you can use for your own reference and as reliable sites to which to send patients. A list of available online training materials is also identified.

Support material for conversations with stakeholders

Part II



This part of the action guide is divided into four sections:

Section 5 Making the case for protection

Section 6 Useful hand-outs to support conversations with parents

Section 7 Frequently asked questions:
Talking with parents about infant and childhood immunisation

Section 8 Links



PHOTO: MIKHAIL ION

Section 5

Making the case for protection

Summary messages

- 5.1 Vaccines reduce suffering and save lives: a public health success story.
- 5.2 Vaccines are safe and effective: the diseases they prevent can cause permanent disability or even death.
- 5.3 Vaccines protect everyone.
- 5.4 Vaccine safety - example Canada.
- 5.5 Global vaccine success stories.
- 5.6 Vaccine vigilance - Measles in the EU 2011.

5.1: Vaccines reduce suffering and save lives: a public health success story

Statistics demonstrate dramatic declines in vaccine-preventable diseases when compared with the pre-vaccine era.

US data on vaccine-preventable disease reporting pre-vaccination and 2011

Disease	Pre-Vaccine Era Estimated Annual Morbidity*	Most Recent Reports [†] or Estimates [‡] of U.S. Cases	Percent Decrease
Diphtheria	21,053	0 [†]	100%
<i>H. influenzae</i> (invasive, <5 years of age)	20,000	243 [§]	99%
Hepatitis A	117,333	11,049 [‡]	91%
Hepatitis B (acute)	66,232	11,269 [‡]	83%
Measles	530,217	6 [†]	>99%
Mumps	162,344	982 [†]	99%
Pertussis	200,752	13,506 [†]	93%
Pneumococcal disease (invasive, <5 years of age)	16,069	4,167 [‡]	74%
Polio (paralytic)	16,316	0 [†]	100%
Rubella	47,745	4 [†]	>99%
Congenital Rubella Syndrome	152	1 [†]	99%
Smallpox	29,005	0 [†]	100%
Tetanus	580	14 [†]	98%
Varicella	4,085,120	449,363 [‡]	89%

*CDC. JAMA, November 14, 2007; 298(18):2155-63

[†]CDC. MMWR, January 8, 2010; 58(51,52):1458-68

[‡]2008 estimates, *S. pneumoniae* estimates from Active Bacterial Core Surveillance

[§]25 type b and 218 unknown

Source: Acquired from www.immunize.org/catg.d/p4037.pdf on August 2012. We thank the Immunization Action Coalition.

Canadian data on vaccine-preventable disease reporting pre-vaccination and in 2007 (25)

DISEASE	Average number of cases and related deaths (per year)	
	Before vaccine	After vaccine
Diphtheria	12,000 cases with 1,000 deaths	0–5 cases with 0 deaths
Tetanus	60–75 cases with 40–50 deaths	0–2 cases and no deaths since 1991
Pertussis	30,000–50,000 cases with 50–100 deaths	3,000 cases with 1–5 deaths
Polio	2,000 cases in last epidemic in 1959	0
Hib	1,500 cases of meningitis and 1,500 cases of infections of blood, bone, lungs, skin, joints	About 30 cases
Measles	95% of children had measles by age 18, or 300,000 cases with 300 deaths, and 300 children with brain damage	Less than 50 cases with 0 deaths
Mumps	30,000 cases	95 cases
Rubella	85% of children have rubella by age 20, or 250,000 cases. About 200 cases of congenital rubella syndrome	25 cases. 0–3 babies with congenital rubella syndrome born to unvaccinated mothers

5.2: Vaccines are safe and effective: the diseases they prevent can cause permanent disability or even death

Disease	Effects of disease	Side effects of vaccine
Diphtheria	Severe sore throat, marked weakness, nerve damage, heart failure. Death in 10% of cases.	DTaP vaccine: 20% of infants have local redness, pain; < 5% have fever; more redness and swelling with booster at 4–6 years.
Tetanus	Toxin affects nerve endings leading to painful muscle spasms and seizures. The spores of this bacterium are present throughout the world in soil. There will always be a need for vaccine protection.	See above for DTaP. Local redness and pain common with adult booster.
Pertussis	Severe spasms of cough lasting 3–6 weeks, pneumonia, convulsions. Brain damage or death in 1 of every 400 infants.	See above for DTaP. The risk of brain damage after pertussis vaccine is too small to be measured.
Polio	Muscle paralysis in 1 out of 100 persons infected with polio. Death in severe cases.	IPV. No risk of disease from vaccine. Given combined with DTaP (see above for side effects).
Hib	Meningitis kills in 5% of cases and leads to brain damage and deafness in 10–15% of survivors.	Given in combination with DTaP/IPV (see above for side effects).

Disease	Effects of disease	Side effects of vaccine
Measles	Severe bronchitis, high fever, rash for 7–14 days; death in 1 per 1,000 cases; encephalitis in 1 per 1,000 cases.	Given combined with mumps and rubella vaccines (MMR). 5–10% have fever with or without rash 8–10 days after vaccine. No risk of disease from vaccine. Risk of encephalitis 1 case per 1 million doses. 1 in 24,000 develops low platelets.
Mumps	Fever, swollen salivary glands. No visible illness in > 50% of cases. Encephalitis in 0.02–0.3% of cases (26); deafness in 1 per 200,000 cases.	See MMR above.
Rubella	Fever, swollen glands, rash. No symptoms in about 50% of cases. Severe damage to foetus if mother infected during first trimester of pregnancy.	See MMR above.
Pneumococcus	Severe infections result in deaths in approximately 30% of children; 15–20% of survivors of meningitis have brain damage, deafness.	Minor local redness, swelling and pain in 15% of recipients.
Varicella	Hospitalization in 1,000 and death in 10 cases/year due to pneumonia, encephalitis, severe skin infections; shingles (zoster) later in life.	Minor local reaction; rash in about 5% of children.

Disease	Effects of disease	Side effects of vaccine
Hepatitis B	Death from complication of chronic infection (cirrhosis, liver cancer) or from severe acute illness. About 90% of infants infected during the first year of life develop chronic infection, compared with 30% of children infected between one and four years, and less than 5% of people infected as adults. In 2002, an estimated 600,000 deaths occurred globally from chronic HBV infection. (27)	Minor local redness, swelling and pain.
Meningo-coccus	Death in 10% of cases; brain damage, deafness, amputations, skin loss in 10% of survivors.	Minor local redness, swelling and pain in 15% of recipients.
Hepatitis A	Death from overwhelming liver damage in a very small proportion of cases. Zero in children under 5 years old to 1.5% in people aged over 60. (28)	Mild pain and redness at injection site.
Human Papilloma-virus (HPV)	Death from cervical and other forms of cancer. HPV infection produces no symptoms. In more than 90% of cases, the infection disappears spontaneously. In the remaining cases it persists, and in 10–12% of these cases, it progresses over the next 20 to 30 years to cancer. (27)	Mild pain and redness at injection site.

Disease	Effects of disease	Side effects of vaccine
Rotavirus	Death from severe dehydration caused by profuse, watery diarrhoea. Potentially fatal diarrhoea occurs in about 1 in every 75 cases (27). Globally, more than two million children are hospitalized for rotavirus infections every year. (29)	No significant reactions.

Source: (25)

5.3: Vaccines protect everyone

Community immunity

This refers to a situation in which a sufficient proportion of a population is immune to an infectious disease (through vaccination and/or prior illness) to make its spread from person to person unlikely. Even individuals not vaccinated (such as new-borns and those with chronic illnesses) are offered some protection because the disease has little opportunity to spread within the community. It is also known as herd immunity. (www.cdc.gov/vaccines/about/terms/glossary.htm#commimmunity)

Figure 1 – When enough people are protected (blue smileys) in a community they can protect some who are not yet immunised (purple smileys) from those who are infected (red smiley)

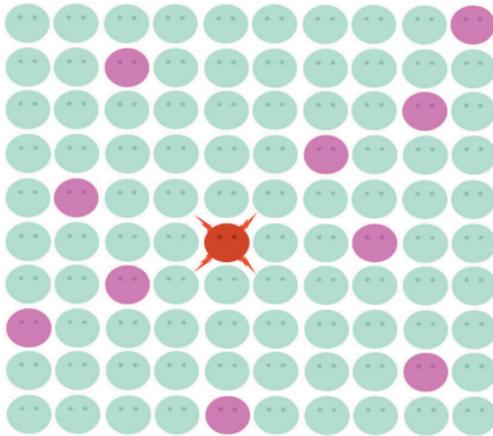
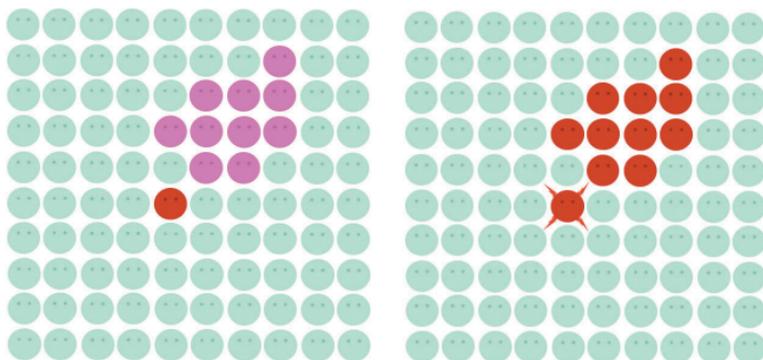


Figure 2 – When large groups of unimmunised accumulate, community immunity doesn't work



Source: Danielsson N. Measles presentation at the ECDC Risk Communication Training Development Meeting Stockholm 10-11 May 2012, personal communication.

5.4: Vaccine safety – development and licensing – example Canada^{xix}

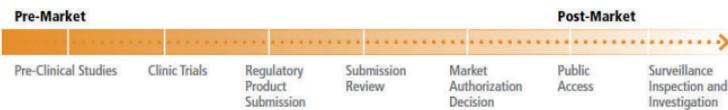
The requirements for licensing vaccines in Canada are held to the highest standard of safety.

Access to vaccines in Canada is a process that involves many steps to ensure safety to the public:

- Health Canada is authorised by the Food and Drug Act and Regulations to regulate the safety, efficacy and quality of vaccines in Canada.

^{xix} Each country should insert their own development and licensing procedures.

- Health Canada’s Health Products and Food Branch are responsible for the review process of any new vaccine sold in Canada.
- This process is on a spectrum from Pre-Market to Post-Market and involves the following steps:



- The Biologics and Genetic Therapies Directorate (BGTD) of Health Canada regulate vaccines used in Canada.
- The BGTD follows an approval process for vaccines with three main steps: Production, Safety & Potency.
- A vaccine can only be considered for approval once sufficient scientific evidence has been collected to show that it is safe, effective and of suitable quality.

The Precautionary Principle

In response to a growing anti-immunisation movement, regulatory authorities now operate under the Precautionary Principle.

This principle strives to eliminate all risks – real or perceived.

The precautionary principle essentially states that where there is uncertainty as to the existence or extent of risks to human health, the (regulatory) institutions may take protective measures without having to wait until the reality and seriousness of those risks become apparent.



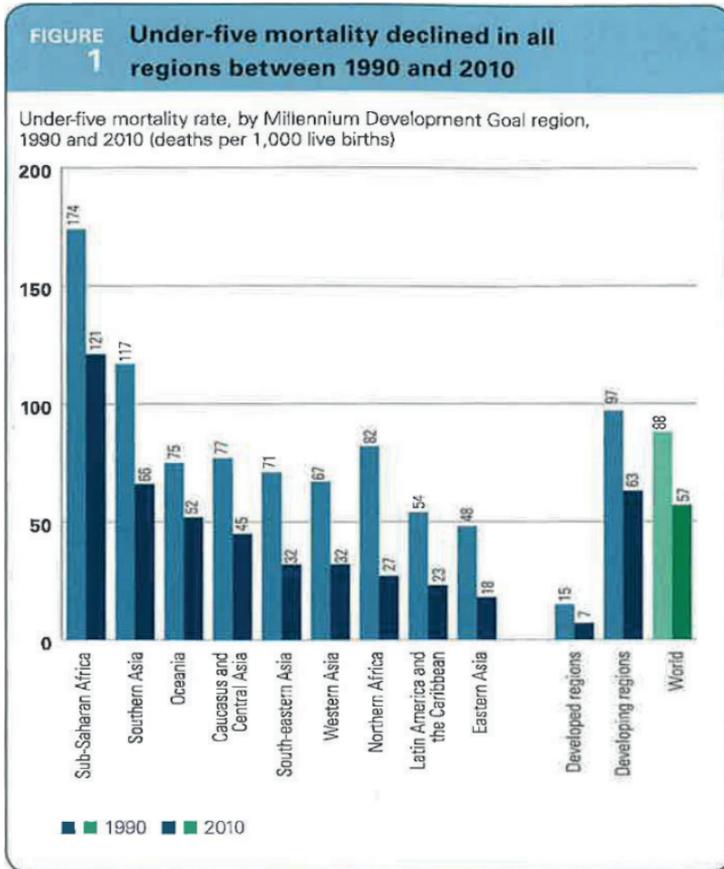
An example of this is the removal of thimerosal from vaccines. In order to increase parental confidence, thimerosal was removed from single-dose vaccines, even though scientific data indicated that this policy change was unnecessary. The irony, of course, is that this change of attitude is occurring at a time when vaccines have never been safer, given the stringent regulatory demands and compliance involved in vaccine manufacturing.

Source: (30)

5.5: Global vaccine success stories

“Over half of the (30%) drop in child mortality since 1990 is attributable to immunization.”

Dr Margaret Chan, Director-General, World Health Organization



Source: (31)

- Smallpox was the first disease to disappear because of vaccination. There have been no cases of smallpox anywhere in the world since 1979. Children are no longer vaccinated against smallpox.
- Paralytic polio has been eliminated from most of the world through vaccination. WHO estimates that since the beginning of the Global Polio Eradication Initiative in 1988, five million people are walking today who would have otherwise been paralysed by the polio virus.

Cases dropped from 350,000 in 1988 to 1606 in 2009. Polio remains common in only four countries: Afghanistan, India, Nigeria and Pakistan. A global vaccination program could completely eradicate the disease within the next 5 to 10 years, but ... outbreaks still occur – usually associated with travel (e.g., the Hajj), or sagging vaccination rates (e.g., Tajikistan).

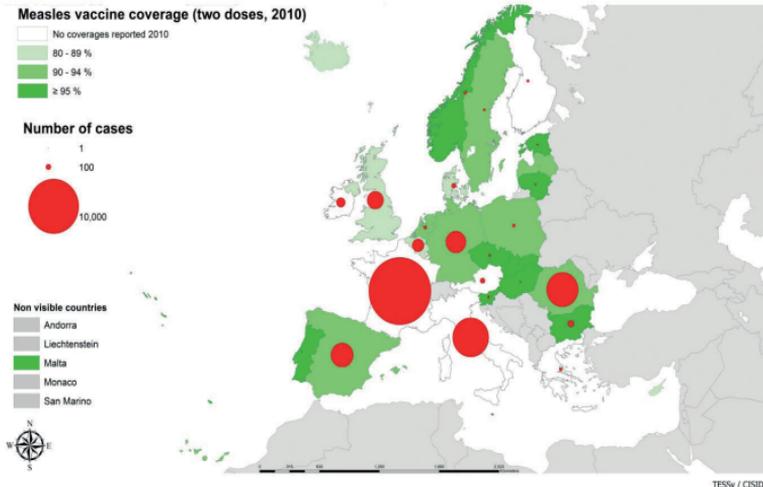
5.6: Vaccine vigilance – Measles in the EU 2011

When vaccination rates decline, rates of disease increase!

- Diphtheria in former Soviet Union: In the late 1980s, former Soviet Union states saw vaccine supplies disrupted, the collapse of their public health system and socioeconomic instability. There was a decrease in childhood immunisation rates. A diphtheria epidemic followed with more than 150,000 cases and 4,000 deaths in the newly independent and Baltic States. A mass vaccination program eventually controlled the epidemic.

- Pertussis in Japan: In the 1970s bad publicity about the pertussis vaccine caused people to stop using it. In the three years before the vaccine was stopped there were 400 cases of pertussis and 10 deaths. In the three years after the vaccine was stopped there were 13,000 cases and 113 deaths. Vaccination was resumed in early 1980..

And now Europe has measles – suboptimal uptake of the MMR vaccine in many countries and accumulation of unvaccinated children has resulted in measles outbreaks. In 2011, 30,567 cases of measles were reported by 29 European countries, a four-fold increase compared to 2009 (7,175). Only two countries in Europe remained measles-free in 2011: Iceland and Cyprus.



(4)



Section 6

Useful hand-outs to support conversations with parents

- 6.1 A HCP vaccination letter and policy.
- 6.2 How vaccines work.
- 6.3 Vaccine schedules.
- 6.4 Vaccine information, schedule trackers and reminders.
- 6.5 Vaccination session overview.
 - 6.5.1 Pre-vaccination Q&A.
 - 6.5.2 Information for parents about vaccine sessions.
 - 6.5.3 Information for parents who refuse or delay vaccination.
 - 6.5.4 Refusal to vaccinate form.

6.1: A HCP vaccination letter and policy

Some HCPs have proactively communicated with parents and issue vaccination policies.

Letter to parents (32)

To Our Patients,

Our practice has experienced a marked increase in parents requesting to delay or decline vaccinations. This may be a result of “scare” stories people have heard or read on the internet or as a result of the tremendous increase in the numbers of vaccines and injections in recent years.

I find myself spending an inordinate amount of time defending our use of vaccines in each well-child check, as well as during increasing numbers of telephone calls. Furthermore, I find myself on the defensive side more often than not.

In response to this heightened demand on our time and energy, I have developed a vaccine policy statement that is posted in every exam room and included in information we give out at the one week well visit. The response has been tremendous! New parents clearly know where we stand in the vaccine “controversy”, and our established patient families have expressed their appreciation for confirming choices they made with their children.

Sincerely,

Get protected and protect: that is our advice!

A Vaccine Policy Statement (32)

I firmly believe in the effectiveness of vaccines to prevent serious illness and to save lives.

I firmly believe in the safety of our vaccines.

I firmly believe that all children and young adults should receive all of the recommended vaccines according to the schedule published by XXXX.

I firmly believe that vaccinating children and young adults may be the single most important health-promoting intervention we perform as health care providers, and that you can perform as parents/caregivers. The recommended vaccines and their schedule given are the results of years of scientific study and data gathering on millions of children by thousands of our brightest scientists and physicians.

These things being said, I recognise that there has always been and will likely always be conflicting feelings surrounding vaccination. As parents we always want the best for our children and actively giving them vaccinations that can have some side effects can be frightening. Vaccines are truly victims of their own success. It is precisely because vaccines are so effective at preventing illness that we are even discussing whether or not they should be given. Because of vaccines, many of you have never seen a child with polio, tetanus, whooping cough, bacterial meningitis or even chickenpox, or known a friend or family member whose child died of one of these diseases. Such success can make us complacent or even

lazy about vaccinating. But such an attitude, if it becomes widespread, can only lead to tragic results.

I am making you aware of these facts not to scare you or coerce you, but to emphasise the importance of vaccinating your child. I recognise that the choice may be a very emotional one for some parents. I will do everything I can to convince you that vaccinating according to the schedule is the right thing to do. However, should you have doubts, please discuss these with me before your visit. In some cases, I may alter the schedule to accommodate parental concerns or reservations. Please be advised, however, that delaying vaccines goes against expert recommendations, and can put your child at risk.

As a medical professional, I feel very strongly that vaccinating children on schedule with currently available vaccines is absolutely the right thing to do for all children and young adults. Thank you for your time in reading this policy, and please feel free to discuss any questions or concerns you may have about vaccines with me.

6.2: How vaccines work

The Immune System

Every day, the body is bombarded with bacteria, viruses, and other antigens. When a person is infected with a disease-causing antigen, the immune system defends against it. In the process, the body produces substances known as antibodies against that specific antigen. The antibodies eliminate the antigen from the body. The next time the person encounters the antigen, the circulating antibodies quickly recognise and eliminate it before signs of disease develop. This is immunity.

1. Passive Immunity

- Usually lasts only a few weeks or months.
- Often provides effective protection for the short term.

Examples of passive immunity are:

- Immunity infants receive from their mothers during the last two months of pregnancy when antibodies are transferred across the placenta from mother to child.
- Injection of blood products such as immunoglobulins used for post-exposure prophylaxis for several diseases including hepatitis A and B, rabies, tetanus and varicella.

Note: Breastfeeding has numerous benefits for infants and is known to enhance the immune response to certain vaccines. It does not provide complete protection against specific vaccine preventable disease.

2. Active Immunity

- Usually lasts for many years, often for a lifetime.
- The immune system is stimulated to produce antigen-specific humoral (antibodies) and cellular immunity.

Active immunity can be achieved in two ways:

Natural Disease	Vaccine-Induced
Bacteria or virus is acquired naturally from the environment	Bacteria or virus is inserted into the body via vaccine serum
The germ or invader is live and active and reproducing	The invading germ from a vaccine may be live, inactivated, or contain only part of the bacteria or virus
The individual may or may not become sick from the invader depending on how well the body's immune system responds	The vaccinated person cannot become sick unless a live vaccine such as MMR or varicella is given, in which case they could possibly experience a much milder form of the disease post-vaccination.

Vaccines interact with the immune system to produce a response similar to one produced by natural infection—but without the risks or potential complications of the disease.

Two Types of Vaccines:

The more similar the vaccine and the reaction are to the natural disease, the more effective the immune response will be.

Live Attenuated

- Produced in a laboratory by modifying a disease-producing bacteria or virus.
- Able to replicate and produce immunity, but usually does not cause illness, e.g., MMR, yellow fever, and varicella vaccines.

Inactivated

- Inactivated vaccines are composed of either whole bacteria or viruses, or a fraction of either with a protein or polysaccharide base.
- Protein-based vaccines contain toxoids (inactivated bacterial toxins) such as tetanus.

- Polysaccharide-based vaccines are composed of pure cell-wall from a bacterium.
- Conjugate polysaccharide vaccines (chemically linked to a protein) are more potent. (30)

6.3: Vaccination schedule

There are different immunisation schedules for each country. You can find yours updated at this website: <http://ecdc.europa.eu/en/activities/surveillance/euvac/schedules/Pages/schedules.aspx>

Sample summary chart – vaccination schedule for United Kingdom

	DTaP	IPV	Hib	MenC	PCV	MMR	HPV ^{6,7}	HepB ^{6,8}	BCG ^{6,9}	Td
At birth								Yes	Yes ¹⁰	
1 month								Yes		
2 months	Yes ¹	Yes ¹	Yes ¹		Yes			Yes		
3 months	Yes ¹	Yes ¹	Yes ¹	Yes						
4 months	Yes ¹	Yes ¹	Yes ¹	Yes	Yes					
Around 12 months								Yes		
Between 12-13 months			Yes ^{2,3}	Yes ^{2,3}	Yes ³	Yes ³				
3 years 4 months-5 years	Yes ⁴	Yes ⁴				Yes				
12-13 years							Yes			
13-18 years		Yes ⁵								Yes ⁵

The United Kingdom Childhood Vaccination Schedule as at 11 February 2011

- ¹ DTaP, IPV and Hib are given as a combined vaccine.
- ² Hib and MenC are given as a combined vaccine.
- ³ These vaccinations should not be given before the first birthday.
- ⁴ DTaP (or dTaP) and IPV are given as a combined vaccine.
- ⁵ Td and IPV are given as a combined vaccine.
- ⁶ These vaccines are offered selectively.
- ⁷ HPV is offered to girls only.
- ⁸ Hepatitis B vaccination is recommended for selected high-risk groups only. This includes babies born to mothers who are chronic carriers of hepatitis B virus or to mothers who have had acute hepatitis B during pregnancy (plus their close family members).
- ⁹ In addition to the recommendations for targeted and high-risk group infants to receive BCG (see below 10) the BCG vaccination policy extends to:
 - Previously unvaccinated new immigrants from high prevalence countries for TB.
 - Children who after screening for TB risk factors test negative to the Mantoux test.
- ¹⁰ BCG is recommended for:
 - All infants (aged 0-12 months) living in areas in the UK where the annual incidence of TB is 40/100,000 or greater.
 - All infants (aged 0-12 months) whose parents or grandparents were born in a country with an annual TB incidence of 40/100,000 or higher.
 - Previously unvaccinated, tuberculin-negative new entrants under 16 years born in/lived in a country with an annual TB incidence of 40/100,000 or greater.

Source: Acquired from <http://www.immunize.org/catg.d/p4010.pdf> on August 2012. We thank the Immunization Action Coalition.

Routine childhood vaccines

5-in-1 (DTaP-IPV-Hib): Protects against diphtheria, tetanus, pertussis, polio, and bacterial infections caused by Hib (*Haemophilus influenzae* type b), including meningitis (a brain infection), and other serious infections

MMR: Protects against measles, mumps, and rubella

Hepatitis B vaccine

Varicella (chickenpox) vaccine

Seasonal influenza ("flu") vaccine

Tdap: Tetanus, diphtheria and pertussis booster for teens and adults

• **Pneumococcal vaccine:**

Protects against bacterial infections caused by *Streptococcus pneumoniae*, including meningitis, pneumonia, and ear infections

• **Meningococcal vaccine:**

Protects against bacterial infections caused by *Neisseria meningitidis*, including meningitis and septicemia, a serious blood infection

• **HPV vaccine:** Protects against human papillomavirus types that cause cervical/vaginal cancer and genital warts

• **Rotavirus vaccine:** Prevents rotavirus diarrhea

Source: (25)



Immunizations for Babies

A Guide for Parents

These are the vaccinations your baby needs!

At birth	HepB
2 months	HepB + DTaP + PCV + Hib + Polio + RV 1–2 mos ¹
4 months	HepB ² + DTaP + PCV + Hib + Polio + RV
6 months	HepB + DTaP + PCV + Hib ³ + Polio + RV ⁴ + Influenza ⁵ 6–18 mos ¹
12 months and older	MMR + DTaP + PCV + Hib + Chickenpox + HepA ⁶ + Influenza ⁵ 12–15 mos ¹ 15–18 mos ¹ 12–15 mos ¹ 12–15 mos ¹ 12–15 mos ¹ 12–23 mos ¹

Check with your doctor or nurse to make sure your baby is receiving all vaccinations on schedule. Many times vaccines are combined to reduce the number of injections. Be sure you ask for a record card with the dates of your baby's vaccinations; bring this with you to every visit.

Here's a list of the diseases your baby will be protected against:

HepB: hepatitis B, a serious liver disease

DTaP: diphtheria, tetanus (lockjaw), and pertussis (whooping cough)

PCV: pneumococcal conjugate vaccine protects against a serious blood, lung, and brain infection

Hib: *Haemophilus influenzae* type b, a serious brain, throat, and blood infection

Polio: polio, a serious paralyzing disease

RV: rotavirus infection, a serious diarrheal disease

Influenza: a serious lung infection

MMR: measles, mumps, and rubella

HepA: hepatitis A, a serious liver disease

Chickenpox: also called varicella

Footnotes to above chart:

1. This is the age range in which this vaccine should be given.
2. Your baby may not need a dose of Hep B vaccine at age 4 months, depending on the vaccine used. Check with your doctor or nurse.
3. Your baby may not need a dose of Hib vaccine at age 6 months, depending on the vaccine used. Check with your doctor or nurse.
4. Your baby may not need a dose of RV vaccine at age 6 months, depending on the vaccine used. Check with your doctor or nurse.
5. All children age 6 months and older should be vaccinated against influenza in the fall or winter of each year.
6. Your child will need 2 doses of HepA vaccine, given at least 6 months apart.

Technical content reviewed by the Centers for Disease Control and Prevention, March 2011.

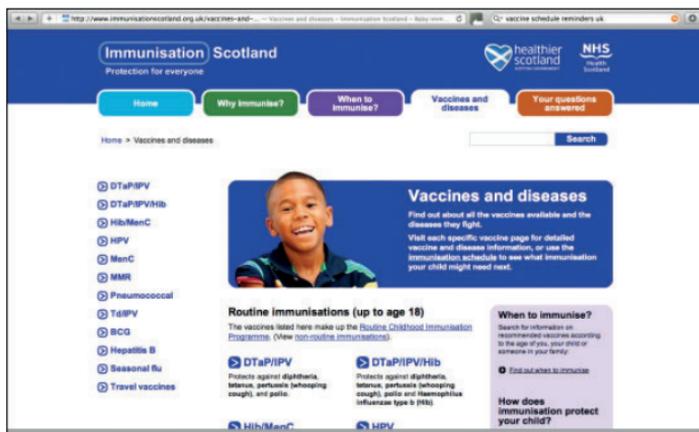
www.immunize.org/catg.d/p4010.pdf • Item #P4010 (3/11)

Immunization Action Coalition • 1573 Selby Ave. • St. Paul, MN 55104 • (651) 647-9009 • www.vaccineinformation.org • www.immunize.org

6.4: Vaccine information, schedule trackers and reminders

A wide variety of vaccine information hand-outs, web-based resources, model schedule formats and reminder options have been developed by different countries and localities. Useful links include:

1. Scottish government website with vaccination information and schedule trackers and reminders.
www.immunisationscotland.org.uk/when-to-immunise/immunisation-schedule.aspx



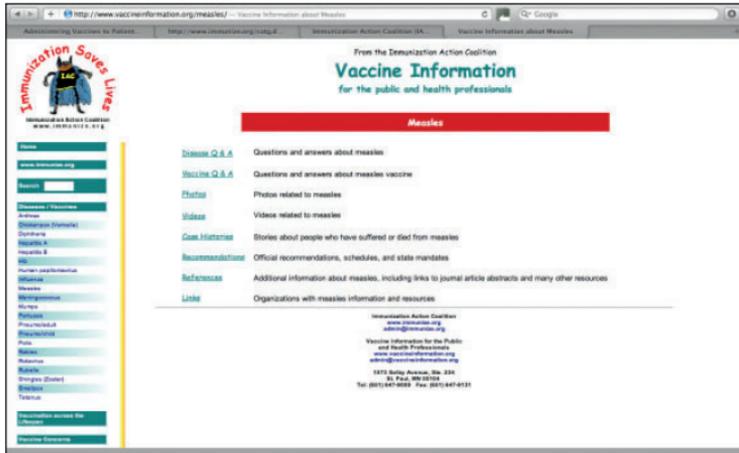
2. Mobile phone application for parents to track children's immunisation schedules.
<https://www.irishhealth.com/cvt/app.html>



3. A wide variety of model resources, from printable hand-outs to mobile phone applications (CDC).
www.cdc.gov/vaccines/schedules/easy-to-read/child.html
4. A personalised schedule maker from British Columbia, Canada.
<http://immunizebc.ca/reminder>

5. An excellent resource for parent vaccine information from a US-based NGO.

www.vaccineinformation.org



6.5: Vaccination session overview

Hand-outs related to pre-vaccination and vaccination session are included.

6.5.1: Pre-vaccination Q&A

Should my child get immunised today?

Q: *What if my child is ill?*

A: *There are very few medical reasons to delay immunisation. Babies and children with minor coughs and colds, or those on antibiotics, can be immunised safely and effectively. However, if your child has a high temperature, the immunisation should be put off until your child is better. If you are worried about whether*

your child is fit to be immunised, talk it over with the doctor or nurse before putting off the immunisation.

Q: What if my child was premature, had a low birth weight or had jaundice?

A: *In general, premature babies should be immunised as normal. It is important that premature babies are protected because they are more vulnerable to certain infections. If your child had a very low birth weight, you should discuss their immunisation needs with your paediatrician. Babies who had jaundice after being born and those who are being breast fed should be immunised as normal.*

Q: What if my child has a serious disease?

A: *It is very important that children with serious diseases are immunised because they are often more at risk from complications of infections. Children with stable neurological conditions such as cerebral palsy or Down's syndrome should be immunised as normal.*

However, care is needed if the child's illness, or its treatment, may lower their immunity. Immunisation should be carefully considered for children with cancer or an immune deficiency disorder, or who are taking medicines which may reduce their ability to fight infection. Discuss this with your doctor.

Children who have had a blood transfusion or received blood products should not get their MMR vaccine until three months after the transfusion.

Q: What if my child has asthma, eczema or hay fever?

A: *Children with asthma, eczema, hay fever and allergies should be immunised, even if they have a severe allergy to eggs (for example, hives (red itchy bumps), swelling of the mouth or throat, difficulty breathing, wheezing, low blood pressure and shock).*

Children taking steroids by inhaler or in a low-dose steroid cream should be immunised as normal. If you have any doubts, talk to the doctor or nurse giving the immunisation.

Q: Can my child get the MMR and other vaccines if they are allergic to eggs?

A: *The MMR vaccine can be given to children with an egg allergy. Your child simply disliking eggs or having diarrhoea or stomach pains after eating eggs is not a reason to avoid the MMR immunisation, and you do not need to take any special precautions. If you have any doubts, talk to the doctor or nurse giving the immunisation.*

Flu vaccine should not be given to those who have a severe allergy to eggs.

Q: What if my child has epilepsy or has had convulsions (fits)?

A: *These children should still be immunised if their condition is stable. Some children get convulsions if they have a high temperature or a fever. If they get a high fever (over 39.5°C) after they have been vaccinated, give them paracetamol or ibuprofen. Children with a family history of fits or epilepsy should be immunised as normal.*

Q: What if my child has recently had, or is due to have, surgery?

A: Do not put the immunisation off if your child is due to have an operation or has recently had one. Having surgery is not a reason to put off immunisation, and a recent immunisation is not a reason to put off surgery.

Q: What if my child has already had one of the vaccine-preventable diseases?

A: You should still immunise your child against these diseases, even if they have had them. It is important to be protected against all the diseases the vaccine covers, even if the child has caught one of the diseases before. This is very important as children under two years do not get enough natural immunity following illness with haemophilus influenza, meningococcal or pneumococcal disease.

Q: Can my child be immunised while they are in close contact with someone who is pregnant?

A: Yes. There is no problem with giving routine immunisations to a child who is in close contact with someone who is pregnant. In fact, immunising the child will protect the mother from being exposed to diseases like rubella.

Q: Do some children also need other vaccines?

A: Yes. Children who have had their spleens removed or have cystic fibrosis, an immune deficiency, chronic heart, lung, liver or kidney disease, sickle cell disease or diseases such as diabetes are more vulnerable to some infections. If your child has any long-term

illness, ask your doctor if they need to be immunised against diseases like flu or hepatitis.

If you are travelling to another country, remember to find out if your child needs any special vaccines.

Immunisation against infectious disease has saved more lives than any other public health intervention apart from providing clean water.

(Adapted by ECDC from the original from the HSE National Immunisation Office - www.immunisation.ie/en/Downloads/NewmaterialsApril2011/PDFFile_16756_en.pdf)

6.5.2: Information for parents about vaccine sessions

Vaccine Sessions – Before, During and After

A. Before the immunisation visit

A.1 *If you have a vaccination record card for your baby, take it along* so the provider can mark the injections given to her/him today. If she/he is getting her/his first vaccination(s), ask for a card. This record could come in handy later to show that your child has had the vaccinations. Your baby's vaccines may also be entered into an electronic registry, or immunisation information system.

A.2 *Be prepared to answer questions* about allergies, immune system problems, or any severe reaction to a previous dose of any vaccine.

B. During the immunisation visit

B.1 *Your provider will ask you some questions* (or give you a short questionnaire to fill out) to make sure that your

child is well and able to get the scheduled vaccination. If your baby has a fever or severe cold or other illness, you might be asked to postpone vaccinations until he/she gets better.

B.2 Your provider will give you information about each vaccine your child receives, including its risks and benefits. Always ask your provider if you have any questions or would like more information.

B.3 Your provider might ask you to hold your baby in a certain way to steady the arm or leg where the injection will be given. These techniques are designed to keep her/him still without actually holding her/him down or frightening her/him.

B.4 Many providers like to keep a child in the office for observation for about 15 or 20 minutes after getting vaccines, in the unlikely event of an allergic reaction.

B.5 Be sure that any vaccinations that are given are recorded in your baby's immunisation record and that you know when to come back for the next vaccinations.

C. After the Immunisation Visit

C.1 Sometimes a child will have a fever or a sore leg or arm (where the injection was given) after an immunisation visit. You can give your child a non-aspirin pain reliever to reduce any pain or fever that might follow vaccinations. Giving the child plenty of fluids to drink can also help reduce a fever. A cool, wet washcloth over the sore area can help relieve pain.

C.2 Serious reactions are uncommon. If your baby:

- cries for three or more hours without stopping;
- seems limp or unresponsive;

- starts having seizures (convulsions);
- has signs of severe allergic reaction (very unlikely) including difficulty breathing, dizziness, swelling of the throat, hives, fast heartbeat, hoarseness or wheezing; or,
- if you are worried at all about how your baby looks or feels call your provider right away.

[Adapted by ECDC from the original by The Vaccine Education Center at The Children’s Hospital of Philadelphia (33)]

6.5.3: Information for parents who refuse or delay vaccination

Sample Q&A – Delaying vaccination

Parent: *Is it ok to delay vaccination?*

Health care provider: *Delaying vaccines will increase the period of time during which children are at risk for vaccine-preventable diseases. Several of these diseases, like chickenpox, pertussis (whooping cough) and pneumococcus (which causes bloodstream infections, pneumonia and meningitis) are still fairly common. Delaying or withholding vaccines only increases the time during which children are at unnecessary risk for severe and occasionally fatal infections. Although the vaccine schedule can look intimidating, it is based upon the best scientific information available and is better tested for safety than any alternative schedules.*

Separating, spacing out or withholding vaccines causes concern because infants will be susceptible to diseases for longer periods of time. When a child should receive a vaccine is determined by balancing when the child is at highest risk of contracting the disease and when the vaccine will generate the best immune response.

Finally, changing the vaccine schedule requires additional doctor's visits. Research measuring cortisol, a hormone associated with stress, has determined that children do not experience more stress when receiving two injections as compared with one injection. Therefore, an increased number of visits for individual injections will mean more stressful situations for the child. In addition, there is an increased potential for administration errors, more time and travel needed for appointments, and potentially increased costs.

Delaying or refusing vaccines: risks and responsibilities

With the decision to delay or refuse vaccines, you are taking on an important responsibility that could put your child's and other people's health at risk.

Unvaccinated children may present a risk to people who are at higher risk of infection

One group at high risk for contracting disease is infants who are too young to be vaccinated. For example, the measles vaccine is not usually recommended for babies younger than 9–12 months. Other people at high risk of contracting vaccine preventable diseases are those with weaker immune systems, due to other existing diseases or medications they are taking (such as some people with cancer, autoimmune diseases or transplant recipients).

Please follow these steps to protect your child, your family and others

+ **Keep a vaccination record easily accessible** so that you can report exactly which vaccines your child has received or not received.

+ Any time that your child is ill (and you: make an emergency call; ride in an ambulance; visit a hospital emergency room; or visit your child's doctor or any clinic), you must **tell the medical staff that your child has not received all the vaccines recommended for his or her age**, because the doctor will need to consider the possibility that your child has a vaccine-preventable disease, such as measles, mumps, pertussis or diphtheria. These diseases still occur, and the doctor will need to consider that your child may have one. If your child has a vaccine-preventable disease, the health care workers who help your child can take precautions, such as isolating your child, so that the disease does not spread to others.

+ Keep your child's school, childcare facility and other caregivers updated on your child's vaccination status.

Be aware that unimmunised children can catch diseases from people who don't have any symptoms. You cannot tell who is contagious. When there is vaccine-preventable disease in your community, it may not be too late to get protection by getting vaccinated. Ask your child's doctor. If there are cases (or, in some circumstances, a single case) of a vaccine-preventable disease in your community, you may be asked to take your child out of school, childcare or organised activities (for example, playgroups or sports). Your school, childcare facility or other institution will tell you when it is safe for an unvaccinated child to return. Be prepared to keep your child home for several days or up to several weeks.

If you know your child has been exposed to a vaccine-preventable disease for which he or she has not been vaccinated:

- Learn the early signs and symptoms of the disease.
- Seek immediate medical help if your child or any family members develop early signs or symptoms of the disease.
- **IMPORTANT:** Notify your doctor, local medical facility, ambulance or emergency room personnel that your child has not been fully vaccinated before medical staff have contact with your child or your family members. They need to know that your child may have a vaccine-preventable disease so that they can treat your child correctly as quickly as possible. Medical staff also can take simple precautions to prevent diseases from spreading to others if they know ahead of time that their patient may have a contagious disease.
- Follow recommendations to isolate your child from others, including family members, and especially infants and people with weakened immune systems.
- Be aware that for some vaccine-preventable diseases, there are medicines to treat infected people and medicines to keep people they come in contact with from getting the disease.
- Ask your health care provider about other ways to protect your family members and anyone else who may come into contact with your child. Your family may be contacted by the state or local health department who track infectious disease outbreaks in the community.

If you travel with your child:

- Review the World Health Organization travel information website (www.who.int/topics/travel) before travelling to learn about possible disease risks and vaccines that will protect your family. Diseases that vaccines prevent remain common throughout the world.
- If you are aware that you or your child has a vaccine-preventable disease, do not spread disease to others. Do not travel in such condition, as you or other family members could still be infectious. If an unimmunised person develops a vaccine-preventable disease while travelling, to prevent transmission to others he or she should not travel by a plane, train or bus until a doctor determines the person is no longer contagious. In certain instances, public health authorities may prevent you from travelling, due to the risk of disease spreading.

Check your own status:

- Make sure to check your own immunisation status, as you are putting your child at risk of disease when you are not fully vaccinated.

(Adapted by the ECDC from the original WHO Euro)

6.5.4: Refusal to vaccinate form

All parents and patients should be informed about the benefits and risks of vaccination. Despite health providers' best efforts to explain the importance of vaccines and to address parental concerns about vaccine safety, some families will refuse vaccination for their children. For parents who refuse one or more recommended immunisations, document your conversation and the provision of information and get the parent to sign the vaccine refusal form and keep the form in the patient's medical record. Revisit the immunisation discussion at each subsequent appointment and carefully document the discussion, including the benefits to each immunisation and the risk of not being age appropriately immunised. This form may be used as a template for such documentation but should not be considered a legal document. This form may be duplicated **or changed** to suit your needs and your patients' needs.

(Adapted by ECDC from the American Academy of Paediatrics)

Refusal to vaccinate form

Child's Name:

Child's ID #

Parent's/Guardian's Name:

My child's health provider has advised me that my child (named above) should receive the following vaccines:

Recommended

Declined

- | | |
|--|--------------------------|
| <input type="checkbox"/> Hepatitis B vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Diphtheria, tetanus, acellular pertussis (DTaP or Tdap) vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Diphtheria tetanus (DT or Td) vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> <i>Haemophilus influenzae</i> type b (Hib) vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Pneumococcal conjugate or polysaccharide vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Inactivated poliovirus (IPV) vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Measles-mumps-rubella (MMR) vaccine. | <input type="checkbox"/> |
| <input type="checkbox"/> Varicella (chickenpox) vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Influenza (flu) vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Meningococcal conjugate or polysaccharide vaccine | <input type="checkbox"/> |
| <input type="checkbox"/> Hepatitis A vaccine | <input type="checkbox"/> |

Recommended

- Rotavirus vaccine
- Human papillomavirus vaccine
- Other

Declined

-
-
-

I have had the opportunity to discuss this with my child's doctor or nurse, who has answered all of my questions regarding the recommended vaccine(s). I understand the following:

- The **purpose** of and the need for the recommended vaccine(s).
- The **risks and benefits** of the recommended vaccine(s).
- If my child does not receive the vaccine(s) according to the medically accepted schedule, **the consequences** may include:
 - Contracting the illness the vaccine should prevent (The outcomes of these illnesses may include one or more of the following: certain types of cancer, pneumonia, illness requiring hospitalisation, death, brain damage, paralysis, meningitis, seizures, and deafness. Other severe and permanent effects from these vaccine-preventable diseases are possible as well.)
 - Transmitting the disease to others.
 - Requiring my child to stay out of child care or school during disease outbreaks.

- My child's health provider, my national ministry/ department of health and the European Centre for Disease Control all strongly recommend that the vaccine(s) be given according to recommendations.

Nevertheless, I have decided at this time to decline or defer the vaccine(s) recommended for my child, as indicated above. I know that failure to follow the recommendations about vaccination may endanger the health or life of my child and others with whom my child might come into contact. I know that I may readdress this issue with my child's health provider at any time and may change my mind and accept vaccination for my child anytime in the future. I acknowledge that I have read this document in its entirety and fully understand it.

Parent/Guardian Signature

Date

Witness

Date

I have had the opportunity to re-discuss my decision not to vaccinate my child and still decline the recommended immunisations.

Parent's initials _____ Date _____

Parent's initials _____ Date _____



Section 7

Frequently asked questions

- 7.1 Autism.
- 7.2 Number of vaccines.
- 7.3 Vaccine ingredients.

“Health providers need to provide parents with balanced and evidence-based information to help them make informed decisions regarding vaccination.”

Dr Marc Sprenger, Director, ECDC

7.1: Autism ^{xx}

Some parents of children with autism are concerned that vaccines are the cause. Their concerns centre on three areas: the combination measles-mumps-rubella (MMR) vaccine; thimerosal, a mercury-containing preservative previously contained in several vaccines; and the notion that babies receive too many vaccines too soon.

Q. What are the symptoms of autism?

A. Symptoms of autism, which typically appear during the first few years of life, include difficulties with behaviour, social skills and communication. *Specifically, children with autism may have difficulty interacting socially with parents, siblings and other people; have difficulty with transitions and need routine; engage in repetitive behaviours such as hand flapping or rocking; display a preoccupation with activities or toys; and suffer a heightened sensitivity to noise and sounds. Autism spectrum disorders vary in the type and severity of the symptoms they cause, so two children with autism may not be affected in quite the same way (34).*

Q. What causes autism?

A. The specific cause or causes of autism in all children are not known. *But one thing is clear: autism spectrum disorders are highly genetic. Researchers figured this out by studying twins. They found that when one identical twin*

^{xx} Adapted from information sheets developed by The Vaccine Education Center at The Children's Hospital of Philadelphia and Wellington-Dufferin-Guelph Public Health (33, 30).

had autism, the chance that the second twin had autism was greater than 90 per cent. But when one fraternal twin had autism, the chance that the second twin had autism was less than 10 per cent. Because identical twins have identical genes and fraternal twins don't, these studies proved the genetic basis of autism. More recently, researchers have successfully identified some of the specific genes that cause autism. Some parents wonder whether environmental factors – defined as anything other than genetic factors – can cause autism. It's possible. For example, researchers found that thalidomide, a sedative, can cause autism if used during early pregnancy. Also, if pregnant women are infected with rubella virus (German measles) during early pregnancy, their babies are more likely to have autism (35).

Q. Does the MMR vaccine cause autism?

A. No. *In 1998, a British researcher named Andrew Wakefield raised the notion that the MMR vaccine might cause autism. In the medical journal *The Lancet*, he reported the stories of eight children who developed autism and intestinal problems soon after receiving the MMR vaccine. To determine whether Wakefield's suspicion was correct, researchers performed a series of studies comparing hundreds of thousands of children who had received the MMR vaccine with hundreds of thousands who had never received the vaccine. They found that the risk of autism was the same in both groups. The MMR vaccine didn't cause autism. Furthermore, children with autism were not more likely than other children to have bowel problems (36,37).*

Q. Does thimerosal cause autism?

A. No. Multiple studies have shown that thimerosal in vaccines does not cause autism. Thimerosal is a mercury-containing preservative that was used in vaccines to prevent contamination. In 1999, professional groups called for thimerosal to be removed from vaccines as a precaution. Unfortunately, the precipitous removal of thimerosal from all but some multi-dose preparations of influenza vaccine scared some parents. Clinicians were also confused by the recommendation. Since the removal of thimerosal, studies have been performed to determine whether thimerosal causes autism. Hundreds of thousands of children who received thimerosal-containing vaccines were compared to hundreds of thousands of children who received the same vaccines free of thimerosal. The results were clear: the risk of autism was the same in both groups (38-41).

7.2: Number of vaccines

Because some children could receive as many as 25 injections by the time they are 2-years-old and as many as five injections in a single visit to the doctor, many parents wonder whether it is safe to give children so many vaccines.

Q. Are children receiving too many vaccines too soon?

A. New-borns commonly manage many challenges to their immune systems at the same time. *Although the mother's womb is free from bacteria and viruses, new-borns immediately face a host of different challenges to their immune systems. From the moment of birth, thousands of different bacteria start to live on the surface of the intestines. By quickly making immune responses to these bacteria, babies keep them from invading the bloodstream and causing serious diseases. In fact, babies are capable of responding to millions of different viruses and bacteria because they have billions of immunological cells circulating in their bodies. Therefore, vaccines given in the first two years of life are a "raindrop in the ocean" of what an infant's immune system successfully encounters and manages every day (42).*

7.3: Vaccine ingredients

Some parents are concerned about ingredients contained in vaccines, specifically aluminium, mercury, gelatine and antibiotics. However, parents can be reassured that ingredients in vaccines are minuscule and necessary.

Common vaccine components

[Adapted from Wellington-Dufferin-Guelph Public Health (30)]

Vaccine Components	Function
Preservatives	Prevent bacterial or fungal contamination (e.g. phenol, 2-phenoxyethanol, thimerosal [refer to section on thimerosal and mercury]).
Adjuvants	Stimulate production of antibodies to fight off diseases and aid other vaccine components in their action. For example, adjuvants may be added to help promote an earlier response, more potent response, or more persistent immune response to disease (e.g. aluminum salts, aluminum hydroxide, aluminum phosphate, potassium aluminum sulphate [alum]).
Additives	Stabilize vaccine from adverse conditions such as freeze-drying, heat, light, acidity, and humidity. Help prevent immunogens from adhering to the side of the vial (e.g. sugars [sucrose, lactose], amino acids [glycine, monosodium salt of glutamic acid], and proteins [gelatin or human serum albumin]).
Inactivating Agents	Separate a pathogen's immunogenicity from its virulence by eliminating the harmful effects of bacterial toxins or removing the ability of the virus to replicate (e.g. formaldehyde, beta-propiolactone, glutaraldehyde).
Antibiotics	Prevent bacterial contamination during manufacturing process (e.g. neomycin, streptomycin, polymixin B, chlortetracycline, amphotericin B).
Cellular Residuals	Egg Proteins – residual amounts found in vaccines made in egg (influenza, yellow fever vaccine) or propagated in chick embryos (MMR vaccines). Yeast Proteins – residual amounts found in hepatitis B vaccines which are made by transfecting baker's yeast cells with the gene that encodes the hepatitis B surface antigen.

Q. Why is mercury in vaccines?

A. Mercury is contained in some multi-dose preparations of influenza vaccine as a preservative.

Preservatives prevent contamination with bacteria. Early in the 20th century, most vaccines were packaged in vials that contained multiple doses. Doctors and nurses would draw up a single dose and place the vaccine back in the refrigerator. Unfortunately, sometimes bacteria would inadvertently enter the vial and cause abscesses at the site of the injection or bloodstream infections that were occasionally fatal. Preservatives, originally added in the 1930s, solved this problem.

The most common preservative used was thimerosal, a mercury-containing compound. As more vaccines were given, children received greater quantities of thimerosal. By the late 1990s, the American Academy of Paediatrics and the Public Health Service requested that mercury be removed from vaccines to make “safe vaccines safer”. No evidence existed to suggest that thimerosal was causing harm, but they wanted to be cautious. Unfortunately, their caution worried parents who wondered whether mercury in vaccines was causing subtle signs of mercury poisoning or autism. Addressing these concerns, scientists performed several studies, all of which showed that thimerosal at the level contained in vaccines hadn’t caused harm.

Further, because mercury is a naturally occurring element found in the earth’s crust, air, soil and water, we are all exposed to it. In fact, infants who are exclusively breast fed ingest more than twice the quantity of mercury than was contained in vaccines. Today, breast-fed infants ingest 15 times more mercury in breast milk than is contained in the influenza vaccine.

Q. Do vaccines contain additives?

A. Many vaccines contain trace quantities of antibiotics or stabilisers. Antibiotics are used during the manufacture of vaccines to prevent inadvertent contamination with bacteria or fungi. Trace quantities of antibiotics are present in some vaccines. However, the antibiotics contained in vaccines (neomycin, streptomycin or polymyxin B) are not those commonly given to children. Therefore, children with allergies to antibiotics such as penicillin, amoxicillin, sulfa, or cephalosporins can still get vaccines.

Gelatin is used to stabilise live viral vaccines and is also contained in many food products. People with known allergies to gelatin contained in foods may have severe allergic reactions to the gelatin contained in vaccines. However, this reaction is extremely rare.

Q. Why is aluminium in vaccines?

A. Aluminium is used in vaccines as an adjuvant.

Adjuvants enhance the immune response by allowing for lesser quantities of active ingredients and, in some cases, fewer doses. Adjuvants were first used in vaccines in the United States in the 1930s – specifically, aluminium salts. Some people wonder whether aluminium in vaccines is harmful. The facts are reassuring.

First, aluminium is present in our environment; the air we breathe, the water we drink and the food we eat all contain aluminium. Second, the quantity of aluminium in vaccines is small. For example, in the first six months of life, babies receive about 4 milligrams of aluminium if they get all of the recommended vaccines. However, during this same period they will ingest about 10 milligrams of aluminium

if they are breast fed, 40 milligrams if they are fed regular infant formula, and up to 120 milligrams if they are fed soy-based infant formula (43).

Q. Why is gelatin in vaccines?

A. Gelatin is used in some vaccines as a stabiliser.

Stabilisers are added to vaccines to protect the active ingredients from degrading during manufacture, transport and storage. Gelatin, which is made from the skin or hooves of pigs, is of concern because some people (about 1 of every 2 million) might have a severe allergic reaction to it.

Also, because religious groups such as Jews, Muslims and Seventh Day Adventists follow dietary rules that prohibit pig products, some parents are concerned about using vaccines that contain gelatin. However, all religious groups have approved the use of gelatin-containing vaccines for their followers for several reasons: first, vaccines are injected, not ingested (except the rotavirus vaccine, which does not contain gelatin). Second, gelatin in vaccines has been highly purified and hydrolysed (broken down by water), so that it is much smaller than that found in nature. Finally, leaders from these religious groups believe that the benefits of receiving vaccines outweigh adherence to religious dietary laws (44).

Q. Why is formaldehyde in vaccines?

A. Formaldehyde is used during the manufacture of some vaccines to inactivate viruses (like polio and hepatitis A viruses) or bacterial toxins (like diphtheria and tetanus toxins). While most formaldehyde is purified away, small quantities remain. Because formaldehyde is associated with the preservation of dead bodies, its presence in vaccines seems inappropriate. However, it is important to realise that formaldehyde is also a by-product of protein and DNA synthesis, so it is commonly found in the bloodstream. The quantity of formaldehyde found in blood is ten times greater than that found in any vaccine (33).

Q. Are some vaccines made using foetal cells?

A. Foetal cells are used to make four vaccines: rubella, chickenpox, hepatitis A and rabies. Foetal cells used to grow the vaccine viruses were isolated from two elective abortions performed in Sweden and England in the early 1960s.

Some parents wonder why scientists would choose to use foetal cells at all. There are several reasons for this. First, viruses, unlike bacteria, require cells to grow. Second, human cells are often better than animal cells at supporting the growth of human viruses. Third, foetal cells are different from other types of cells in that they are virtually immortal, meaning they can reproduce many, many times before dying. Other cells reproduce only a limited number of times before they die (45).

Q. Do ingredients in vaccines cause allergic reactions?

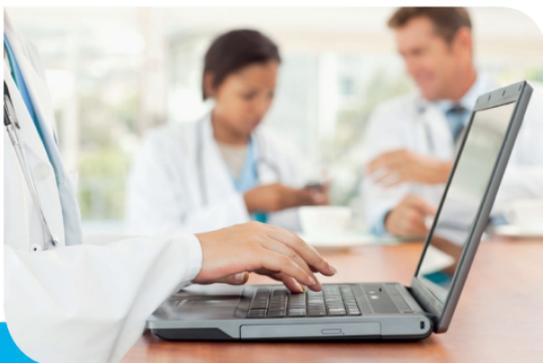
A. In addition to gelatin, other ingredients in vaccines such as egg proteins, antibiotics and yeast proteins might cause an allergic reaction. Because the influenza and yellow fever vaccines are grown in eggs, the final products

contain sufficient quantities of egg proteins to rarely cause an allergic reaction in people allergic to eggs. People with egg allergies can get these vaccines only under special protocols and under appropriate medical supervision (46).

Antibiotics are used to prevent bacterial contamination during production of some vaccines. However, the types of antibiotics used in vaccines, such as neomycin, streptomycin, polymyxin B, chlortetracycline and amphotericin B, are not those to which people are usually allergic.

A couple of viral vaccines are made in yeast cells; these include hepatitis B vaccine and one of the human papillomavirus vaccines (i.e., Gardasil). Although the vaccine is purified away from the yeast cells, about 1 to 5 millionths of a gram remain in the final product. The good news is that people who are allergic to bread or bread products are not allergic to yeast, so the risk of allergy from yeast is theoretical (47).

Section 8



Links

- 8.1 Stories.
- 8.2 List of evidence-based information resources on vaccines and immunisation (selective).
- 8.3 References.

8.1: Stories

a. Video testimonies

Nastasia's story – ECDC/Euronews video

Nastasia has made a spectacular recovery. Just a year ago she was in a coma after contracting measles. The 16-year-old who lives in Valence, in south eastern France, suddenly complained of a sore throat, red spots appeared and she had a high temperature. After one week at 41°C, she was hospitalised, diagnosed with measles encephalitis.



<http://prod-euronews.euronews.net/2012/03/26/eliminating-measles-personal-stories>

Rachel's story – NHS video

Rachel's daughter Lola contracted measles at the age of three. In this video, Rachel describes Lola's symptoms, how she was finally diagnosed with measles and the treatments she received.

Measles is a highly infectious viral illness that can cause fever, coughing and distinctive red-brown spots on the skin. Rachel's daughter Lola contracted measles at the age of three. In this video, Rachel describes Lola's symptoms, how she was finally diagnosed with measles and the treatments she received.

[Find out how to prevent measles](#)

Views: 43,524

Comments & Ratings:
[0 comments](#) | [5 ratings](#)

Credits: NHS Choices



www.nhs.uk/Video/Pages/measles-rachel.aspx

Get the Picture – CDC video

After talking with parents across the country, CDC put together this short video to help answer the tough questions parents had about childhood immunisations.

CDC-TV



Get The Picture: Childhood Immunizations
Source: National Center for Immunization and Respiratory Diseases
Running Time: (6:27)
Release Date: 4/13/2009

After talking with parents across the country, CDC put together this short video to help answer the tough questions that real moms had about childhood immunizations. Understanding the importance of vaccines is crucial for you to protect your children's health.

www.cdc.gov/CDCTV/GetThePicture

Mumps alert – NHS video

We've seen a lot of mumps among students in recent years. In 2011 there were 10,396 cases of mumps in England. School leavers and other young adults should make sure they're fully vaccinated. Dr Rupal Shah explains the symptoms and treatment, and the importance of immunisation.

Mumps



Mumps is a viral infection and is highly contagious. Dr Rupal Shah explains the symptoms and treatment, and the importance of immunisation.

www.nhs.uk/Planners/vaccinations/Pages/Mumpsalert.aspx

b. Written testimonies

Charlotte's story – NHS

Charlotte Sanger's daughter Harriet, 2, had her MMR jab in 2008. Charlotte, 32, a writer and editor at NHS Choices' Southampton office, recalls what went through her mind at the time.

Harriet had already had her routine 5-in-1 and meningitis C jabs when she was two months old. It was an automatic step for her to have these, which I didn't question or worry about. But when she reached her first birthday and it was time for her to have the MMR jab, I had qualms. So did many of my friends with babies the same age.

By this time, all the scare stories (which surfaced in the late 1990s) that the MMR jab could cause autism had been firmly dismissed and the logical side of me knew that the vaccine was safe and beneficial. But as a mum, I still had nagging doubts. I know my worries weren't based on medical facts but I was very cautious about going ahead. The decision for Harriet to have the MMR jab ultimately lay on my shoulders and I felt under pressure to make the right choice.

A friend had looked into having each of the measles, mumps and rubella vaccines as separate single injections, but she told me it was expensive, meant travelling to a private clinic in London and would be six injections rather than just two for the MMR course. That and the fact that I knew there was no evidence to show that single injections were any safer than the combined MMR jab ruled them out as an option.

I did some research of my own into the pros and cons of vaccination, and from what I read, all the evidence showed that the MMR jab was safe and had no links with autism. I talked to a colleague who was a doctor and another friend, who's a nurse. They were both reassuring about MMR and said the benefits far outweighed any potential side effects.

What really made up my mind to take Harriet for her MMR was that I didn't want to risk her catching mumps or measles. I knew both of these illnesses can kill a child. Once I'd made the decision to go ahead, I never looked back. I probably kept a closer eye on Harriet than usual for a day or two after the jab but she was absolutely fine and I forgot about it. With the recent surge in cases of measles, I'm so relieved Harriet had the MMR jab and is protected. I'll definitely be taking her for her pre-school booster.

Source: Acquired from www.immunize.org/catg.d/p4060.pdf on August 2012. We thank the Immunization Action Coalition.

8.2: List of evidence-based information resources on vaccines and immunisation (selective)

Look for Health On the Net quality seal^{xxi} (www.hon.ch) and WHO approved vaccination websites on www.who.int/immunization_safety/safety_quality/approved_vaccine_safety_websites/en/

Source	Link	Language	Comments
Regional International			
European Centre for Disease Prevention and Control (ECDC)	http://ecdc.europa.eu/en/healthtopics/immunisation/Pages/index.aspx	ENG	ECDC page with information links for the general public and health care professionals
GAVI	www.gavialliance.org/	ENG, FR	Information on global vaccine initiatives
WHO	www.who.int/topics/immunization/en/	ENG, AR, CHN, FR, ESP, RUS	Global information

^{xxi} The Health On the Net Foundation (HON) promotes and guides the deployment of useful and reliable online health information, and its appropriate and efficient use. Created in 1995, HON is a non-profit, non-governmental organisation, accredited to the Economic and Social Council of the United Nations. For 15 years, HON has focused on the essential question of the provision of health information to citizens, information that respects ethical standards.

Source	Link	Language	Comments
UNICEF	www.unicef.org/immunization/index_resources.html	ENG, AR, CHN, FR, ESP, RUS	Global information
WHO Regional Office for Europe	http://eiw.euro.who.int/	ENG	Hosts-European Immunisation Week website
EU MS			
NHS – UK - Choices - Health Department	www.nhs.uk/Planners/vaccinations/Pages/Landing.aspx www.dh.gov.uk/en/Publichealth/Immunisation/index.htm	ENG	Different websites targeting public and professional audiences
London School of Hygiene and Tropical Medicine (LSHTM) Vaccine confidence website	www.vaccineconfidence.org/	ENG	Global updates on important vaccine related news
Irish Health Service Executive Immunisation Website- Protect- Prevent- Immunise	www.immunisation.ie/en	ENG	Broad array of information materials

Source	Link	Language	Comments
Network Italiano dei Servizi di Vaccinazione (NIV)	www.levaccinazioni.it	ITA	Broad array of information materials in Italian
Estonian National Health Board	www.vaktsineeri.ee	EST	Broad range of information in Estonian
Berufsverband der Kinder- und Jugendärzte (BVKJ)	www.kinderaerzteimnetz.de	GER	NGO with public audience information in German
Robert Koch Institute	www.rki.de/DE/Content/Infekt/Impfen/impfen_node.html	GER	Broad array of information materials in German
Rijksvaccinatieprogramma (RVP) National Vaccination Programme of the Netherlands	www.rivm.nl/rvp	Dutch	Audience: members of the public and health-care professionals

Source	Link	Language	Comments
Slovenská epidemiologická a vakcinologická spoločnosť	www.ockovanieinfo.sk	SK	Contains evidence-based and user-friendly information on vaccination and related issues
Ministry of Health, Social Services and Equality	www.msssi.gob.es/profesionales/saludPublica/prevPromocion/vacunaciones/vacunasProfesionales.htm www.msssi.gob.es/ciudadanos/proteccionSalud/infancia/vacunaciones/home.htm	ESP	Information materials about immunisation programme for health professionals Information about immunisation programme aimed at the general public
Swedish Institute for Infectious Disease Control (SMI)	www.smittskyddsinstitutet.se/amnesomraden/vaccinationer	SWE	Comprehensive information on infectious disease control that is both factual and easy to understand

Source	Link	Language	Comments
USA			
US Centers for Disease Control and Prevention (CDC)	www.cdc.gov/vaccines	ENG, ESP	Comprehensive information
Advisory Committee on Immunization Practices (ACIP)	www.cdc.gov/vaccines/recs/ACIP/default.htm	ENG	Current recommendation on vaccination
Autism Science Foundation	www.autismsciencefoundation.org	ENG	Good source for current autism research information
The College of Physicians of Philadelphia	www.historyofvaccines.org	ENG	Provides information on vaccines, anti-vaccine movements, fact sheets, information for parents
Immunization Action Coalition	www.immunize.org	ENG	Excellent source of accessible information
Medscape	www.medscape.com/viewarticle/741343	ENG	Interview with Paul Offit on the dangers of the anti-vaccination movement

Source	Link	Language	Comments
National Network for Immunization Information (NNii)	www.nnii.org	ENG SPA	Current updates on practice
PATH	www.path.org/vaccineresources/	ENG	Vaccine resource library
Institute of Medicine	www.iom.edu	ENG	Good source for safety reviews
Polio Eradication	www.polioeradication.org	ENG	Global updates on polio vaccination
Canada			
Public Health Agency of Canada	www.phac-aspc.gc.ca/publicat/cig-gci/index-eng.php	ENG, FR	Canadian Immunization Guide, Seventh Edition (2006)
Canadian Paediatric Society	www.cps.ca	ENG, FR	Good source of information parents and professionals
National Advisory Committee on Immunization, Canada	www.naci.gc.ca	ENG, FR	Guides and safety updates
Health Canada, Public Health Agency of Canada	www.phac-aspc.gc.ca/im/index.html	ENG, FR	Good public and professional information materials

Source	Link	Language	Comments
Canadian Coalition for Immunization Awareness and Promotion	www.immunize.cpha.ca	ENG, FR	Good source of public information
Australia			
Australian Department of Health and Aging – Understanding Childhood Immunisation	http://immunise.health.gov.au/internet/immunise/publishing.nsf/Content/IMM52-cnt	ENG	Understanding Childhood Immunisation booklet
Australian Department of Health	http://immunise.health.gov.au/internet/immunise/publishing.nsf/Content/Handbook-quickguides-sideeffects	ENG	Useful table of comparison of the effects of diseases and the side effects of vaccines in the Australian Immunisation Handbook
National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS)	www.ncirs.edu.au	ENG	Resources include fact sheets on vaccine preventable diseases and vaccine safety, an MMR decision aid for parents

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Annexes



There are four annexes in this section:

- Annex 1** Methodology and approach
- Annex 2** Content developers, advisors, expert interviewees and reviewers
- Annex 3** Questionnaires
- Annex 4** Evaluation



Annex 1: Methodology and approach

This ECDC-supported behavioural communication resource development project was carried-out in four steps.

1.0 Primary and secondary research. A content development team (see Annex 2), based on guidance from ECDC experts, conducted a rapid needs assessment which included:

- a review of previous ECDC vaccination-related technical studies and documents;
- a selective literature and website review based on pub-med and Google searches and expert recommendations; and
- interviews and focus groups with designated target experts, parents (carers), media and representatives from so-called ‘hard-to-reach’ groups.

1.1 ECDC technical studies and documents included:

1.1.1 A literature review on health information-seeking behaviour on the web: a health consumer and health professional perspective (48).

1.1.2 A literature review of trust and reputation management in communicable disease public health (49).

1.1.3 Conducting health communication activities on MMR vaccination (50).

1.1.4 Summaries of studies in process related to risk communication and immunisation web page analysis.

1.2 Selected peer-reviewed and 'grey' literature sources were identified through pub-med and Google searches.

Keywords for pub-med searches included childhood immunisation and vaccination advice and/or communication. These searches yielded approximately 100 articles, ten of which focused on European countries. All abstracts were reviewed. Additionally, articles recommended by interviewed experts were reviewed in full and are included in the reference list. Google searches focused on identifying websites that provided both provider and public vaccination information and advice. We were guided in our searches by WHO's list of vaccine safety websites, ECDC and CDC websites and links. A full list of websites reviewed is included in section 8.2.

1.3 Interviews. The content development team was provided with a list of 40 vaccination, communication and health professional 'experts' to interview by ECDC. Criteria for selection included practical knowledge and experience of conducting, communicating and/or organising vaccination programmes at regional, national and/or local level. All were invited for interview. Twenty accepted (see Annex 2). These experts were either interviewed personally, over the telephone or filled out a written questionnaire (see Annex 3). Findings were then collated and analysed by the content development team. Additionally 20 questionnaires were sent to media (see Annex 3) from the World Health Editor's Network (WHEN) and

World Health Youth (WHY) Environment and Health Communication Network and parents involved in a European School network. Ten of these were returned and analysed.

Focus groups and questionnaires were used to gather data from parents in six EU countries. Four focus groups with 6–12 persons who had direct experience (or assisted others) with seeking and obtaining vaccinations for their children were conducted. Two groups were run in Romania (one with Roma parents and grandparents and one with Roma Health Mediators) and two in Italy (one with Italian mothers and one with immigrant mothers). These groups were run in the local language after which the findings were translated and summarised.

Information gathered from the interviews, focus groups and questionnaires were analysed by the WHCA content development team. Key concerns, questions, and recommendations to strengthen vaccination-related communication and interventions of health care providers gleaned from the different stakeholders were then compared to advice and guidance offered to HCPs in reviewed journal articles and selected websites. Key topic areas were identified and used to develop a first draft of the ‘voice of the stakeholder’ advice presented as the main content of this guide.

2.0 Advisory review. A six-person advisory group was selected for the project by ECDC. The group included

three vaccination and three communication experts (see Annex 2). This group reviewed and commented on the first draft of the guide. Additionally, ECDC staff reviewed and commented on the first draft. Based on these comments a second draft was developed for testing with health care providers.

3.0 HCP review. Fifteen selected health care providers involved with immunisation programmes (and in some cases involved with ‘hard-to-reach’ populations) in the UK, Ireland, Germany and Switzerland were asked to read the second draft and fill in an evaluation questionnaire (see Annex 2). Specific feedback was sought related to format and content, especially the accuracy and relevance of key messages from stakeholders. Based on this feedback a third draft was produced.

4.0 Finalisation. This third draft was then sent to the advisory group and ECDC staff for a second review. Based on their feedback to this third draft, a final fourth draft was agreed.

Annex 2: Content developers, advisors, expert interviewees and reviewers

Content Development Group

World Health Communication Associates:

- Franklin Apfel, UK. Project coordinator, Interviews – Experts, Social Marketing and Media
- Linda Carrier-Walker, Switzerland. Interviews – Experts, Writing and Editing. (I) and Æ
- Sabrina Cecconi, Italy. Project Management and Interviews
- Phil Chamberlain, UK. Interviews – Parents, Editing. (M)
- Alexander Kirby, UK. Interviews – Media. (M)
- Nadia Oprandi, Italy. Focus Groups – Parents and Immigrants in Italy
- Tamsin Rose, Belgium. Focus Groups Roma Parents and Health Mediators, in Romania
- Elie Carrier-Walker, Switzerland. Research and Editing

Advisory Group (All were interviewed and reviewed two drafts)

- Mr Clive Blair-Stevens, Director, Strategic Social Marketing, UK
- Dr Pilar Campos, Medical Doctor Health Promotion Area, Sub-Directorate of Health Promotion and Epidemiology. Directorate General of Public Health, Quality and Innovation. Ministry of Health, Social Services and Equality, Spain
- Dr Paolo D’Ancona, Centro Nazionale di Epidemiologia, Sorveglianza e Promozione della Salute (CNESPS), Italy

- Dr Kuulo Kutsar, State Epidemiologist of Estonia, Advisor in Epidemiology, Editor-in-Chief of EpiNorth Journal, Estonia
- Dr Liesbeth Mollema, Researcher, Epidemiology National Institute for Public Health and the Environment (RIVM) Centre for Infectious Disease Control
- Dr Nick Sevdalis, Psychologist – Senior Lecturer in Patient Safety, Imperial College London, UK

Expert Interviewees (I) and Reviewers (Æ) and Media responders (M)

- Dr Alex Apfel, Senior House Officer, Frenchay Hospital North Bristol NHS Trust, UK Æ
- Ms Sarah Bridgman, Health Visitor, North Somerset Community Partnership, UK Æ
- Mr Robb Butler, WHO Regional Office for Europe, Denmark (I)
- Dr Hana Cabrnociová, Chairperson Society for primary paediatric care ČLS JEP, Czech Republic (I)
- Ms Jill Caughley, RN, MSc Red Cross Primary Care, Geneva, Switzerland Æ
- Dr Anna Clarke, Consultant in Public Health Medicine working in Department of Public Health, Ireland Æ
- Dr Suzanne Cotter, Specialist in Public Health Medicine, HSE – Health Protection Surveillance Centre, Ireland (I) and Æ
- Ms Siobhan Curran, Pavee Point Traveller and Roma Centre, Ireland Æ

- Ms Maria Daly, Pavee Point Traveller and Roma Centre, Ireland Æ
- Dr Niklas Danielsson, Senior expert communicable diseases, Public Health Development section, Public Health Capacity and Communication Unit, ECDC (I)
- Dr Tarik Derrough, Expert Vaccine Preventable Diseases Response and Support Section – Surveillance and Response Support Unit, ECDC (I)
- Dr Irina Dinca, Senior Expert Communicable Diseases Public Health Development section Public Health Capacity and Communication Unit (PHC), ECDC Æ
- Dr Bruce Gellin, Head of National Vaccination Programmes, Washington DC, USA (I)
- Dr Tesfamicael Ghebrehiwet, International Consultant in Nursing and Health Policy, International Council of Nurses Switzerland (I) and Æ
- Mr Romit Jain, Communication officer at Press Office, ECDC (I)
- Dr Bernard Kaic, Specialist in epidemiology, Croatian National Institute of Public Health, Croatia (I)
- Dr Ülla-Karin Nurm, Head of Public Health Development Section, Public Health Capacity and Communication Unit (PHC), ECDC Æ
- Mr Martin Kasarda, Media contact, Slovakia (I)
- Dr Jana Kollarova, Department of Health Promotion Regional Public Health Authority, Kosice Slovakia (I)
- Dr Alenka Kraigher, Head of Communicable Diseases and Environmental Health Centre, National Institute of Public Health, Slovenia (I)

- Dr Pier Luigi Lopalco, Head of the vaccine preventable disease programme, ECDC (I)
- Dr Dario Manfellato, Scientific journalist, columnist of Corriere Salute, weekly supplement on Health of Corriere della Sera, Italy (M)
- Dr Alan McClatchey, General Practitioner, Wroughton-Vale Practice, Churchill, UK Æ
- Dr Jose Navarro, Paediatrician, Head Prevention Service, Directorate of Health Murcia, Spain (I)
- Ms Barbora Neubauerová, Public Health Development Section, Public Health Capacity and Communication Unit (PHC). ECDCÆ
- Ms. Ger O'Connor, Immunisations Community Services Dublin West Cherry Orchard Hospital, Ireland Æ
- Dr Marje Oona, Researcher at University of Tartu, Estonia, Estonian Society of family doctors, Estonian Paediatric Association, Estonia (I)
- Ms Judith Oulton, CEO Oulton consulting, Canada Æ
- Dr Maria Grazia Pascucci, Responsible for Vaccination programs addressed to Children and adolescents at Public Health service –Regione Emilia-Romagna, Italy (I)
- Dr Mircea Popa, “Carol Davila” University of Medicine and Pharmacy, Romania (I)
- Dr Florin Popovici, epidemiologist, Senior expert in the National institute of Public Health, Romania (I)
- Dr Svetla Tsolova, Expert in Monitoring and Surveillance, Public Health Development Section, ECDC Æ

- Mr Franz Wagner, Chief Executive Officer, Director WHO Collaborating Center, German Nurses Association, Germany Æ
- Mrs Irene Wanland, editor-in chief, Swedish Nursing Association Magazine Tidningen Vårdfokus, Sweden. (M)
- Ms Andrea Würz, Information Officer, Public Health Development Section, Public Health Capacity and Communication Unit, ECDC Æ
- Dr Piotr Wysocki, Seconded National Expert, Public Health Development, Public Health Capacity and Communication Unit, ECDC Æ
- Mrs Sara Zinn, Health Visitor, North Somerset Community Partnership, UK Æ

Annex 3: Questionnaires – sample questions

Health workers – Experts

1. State your name, institutional affiliation and role.
2. In what way are you or have you been involved with vaccination delivery?
3. Where on a scale of 0-10 – with 0 being a sceptic to 10 being an active proponent of vaccines – would you place yourself?
4. Please describe a vaccine related intervention that you and/or your institution has taken part in and that you consider a success? What made it a success?
5. What do you believe is your or your institution's biggest challenge related to increasing and/or maintaining high vaccination coverage?

This project aims to produce information materials to strengthen health workers capacities to increase vaccination uptake. To this end:

6. What kind of support and information about vaccinations do health workers need, in your opinion? In what format(s), e.g., postgraduate training courses, factsheets, brochures, posters, audio-visual aids, peer to peer education, communication training, patient testimonies, social media, websites etc., and by whom should this be delivered?
7. What, in your opinion, are the main information needs of families (parents and grandparents in particular) that health workers should address? In what formats should this information be presented? *Ask for good and bad practice examples.*

8. Who in your community and or institution do you consider *hard-to-reach* patients? What are their information needs and how best do you think health workers can reach them? In what formats and by whom should this information be delivered? Ask for examples. Also ask about their opinion about the use of incentives like cash payments or gifts in-kind used in some communities to increase vaccine uptake?
9. In what ways do you feel media affects vaccination uptake? Do you know of health campaigns in the media that have been successful in increasing vaccination uptake? What do you think were the main reasons for that success? What are the information needs of media? In what format(s) should this information be delivered and by whom? Give examples.
10. Are there particularly good articles, persons or projects that you think this project should investigate?
11. What, in your opinion, would make this project a success? What should be criteria for evaluations?

Families (Parents/Grandparents) and hard-to-reach populations

1. State your name and briefly describe your family.
2. Have your children or grandchildren received vaccines?
3. What do you know about vaccines in general? (how they work, efficacy, side effects...)
4. From whom or where do you get your information about health in general (health information) and information on vaccinations in particular?

5. What do you think are the most important vaccinations? And the least important?
6. What do you think about vaccinations in general?
7. What do you know about measles/rubella/mumps? (ways of transmission, severity, complications...)
8. What do you know about the vaccination that is given to protect people from measles/rubella/mumps? (duration, side effects, efficacy...)
9. Which are, in your opinion, the main reasons for vaccinating your child against measles/rubella/mumps? And the main reasons for not vaccinating him/her?
10. Please describe your most recent vaccination experience for one of your children or grandchildren?
11. What did you consider good and/or bad about this experience?
12. Who do you find is the most reliable source of health information? Why?
13. How difficult has it been for you to get yourself or your children vaccinated?
14. What has made it harder or easier?
15. This project aims to produce information materials to strengthen health workers capacities to increase vaccination uptake. What, in your opinion, are the main information needs of parents and grandparents [or hard-to reach e.g., Roma] that health workers should address?
16. What kind of health information is most useful for you in making vaccination choices?

17. In what formats and by whom should this be presented?
What is the best format (verbal information from doctor or nurse, written information, posters, information over the radio, community meetings, information on TV, audio visual information on DVD)?
18. Give good and bad practice examples.
Specifically ask about experience with factsheets, brochures, posters, audio-visual aids, peer-to-peer education, patient testimonies, social media and websites.
What is your feeling about incentives like cash payments used for vaccination?
19. What advice for health care workers would you give to help them increase vaccination rates in your community?

Media

1. Have you been involved with covering vaccination-related news and initiatives? If so, in what way?
2. What in your opinion are some key newsworthy issues related to vaccination, in particular measles vaccination?
3. What is your opinion are the main information needs of parents related to vaccination?
4. What are main information needs of media related to vaccination?
5. What advice do you have for health care providers who are trying to enhance vaccination coverage for vaccine preventable diseases?

Draft Review Feedback

1. What was your overall impression about the guide? Did anything in particular stand out?
2. What do you think worked well? What doesn't work well?
3. What do you think of this 'voice of the stakeholder' approach?
4. Did you find the content relevant to your practice context? If yes, in what ways? If no, why not?
5. How could it be made more relevant?

Annex 4: Evaluation

All of the immunisation, epidemiology, health provider, social marketing and media experts interviewed (Annex 2) were asked for advice on evaluation criteria and indicators related to this guidance. Their insights were further developed with evaluation recommendations sourced from evidence-based websites (p.135-141).

All experts agreed that the key outcome measure (indicator) for this initiative should be its impact on vaccination coverage rates. Has, or has not, vaccination uptake (e.g., MMR – measles, mumps and rubella) by different target groups been increased? Has, or has not, the implementation of the advice in this guidance led to increased population protection from childhood vaccine preventable diseases? The experts also emphasised the importance of disaggregated data that could be used to monitor and compare uptake rates related to different providers, institutions, communities, sub-national areas and social groups.

Additional outcome and process indicators were identified to help providers and implementing agencies identify professional behaviours and program components to be strengthened so that all parents chose to get their children protected by vaccination, particularly those in population groups whose children are currently un- and under-vaccinated. To this end, specific objectives, indicators and checklists were suggested to determine whether:

1. providers are adopting the communication and re-design advice of the parents, social marketers, peers and so-called ‘hard-to-reach’ populations made in this guidance (p. 21-73);
2. health providers were maintaining their vaccination information and administration skills (see p. 48-54); and,
3. the guidance stimulated any changes in the target groups perceptions and behaviours related to protective vaccination programmes.

Process evaluation approaches

Several principles were identified as key for effective process evaluation approaches for this behavioural communication initiative. The principles included the need for health providers and/or agencies to:

1. Engage stakeholders at all stages of evaluation.

Fostering input and participation from parents, experts, media and representatives of hard-to-reach populations helps increase chances that the evaluation will be useful; can improve the evaluation’s credibility; comprehension; enhance cultural competence; help protect human subjects; and, avoid real or perceived conflicts of interest.

- ### **2. Contextualise the evaluation.**
- Customise evaluation approaches to match the features of the practise setting or program being evaluated, including its purpose, place, stage of development and relationships in a larger public health and societal context.

3. See evaluation as a cyclical process. Remember, evaluation is not a linear process. Evaluation is not an end in itself but rather an approach to improving immunisation programs.

4. Ensure that evaluation objectives are SMART:

- Specific (specifying what they want to achieve);
- Measurable (showing if the objectives are being met);
- Achievable (attainable);
- Realistic (achievable with the resources you have);
- Timed (achieved within a set timescale/deadline).

Experts suggested two general approaches here. The identification of ‘advice’ message related objectives, indicators and data sources (see Table 1 for some examples) and the use of ‘advice’ messages as checklists (see Tables 2 and 3).

Table 1: Example of objective/indicator/data source for evaluating implementation of stakeholder advice

Message	Objective	Indicator	Data Source
Section 1: A parent and grandparent perspective – Messages			
Health care providers (HCP) should do what they recommend others to do	Increase HCP vaccination coverage by X%	HCP influenza vaccination coverage	Institutional/ community influenza vaccination registers
Teach us about the dangers of non-vaccination	Raise awareness of dangers of measles by X%	Scores on 5 true/false measles questions	Pre and post HCP visit parent surveys
Inform and remind people about appointments, schedules and where they can get reliable information	Increase second measles vaccine uptake by X%	Number receiving second measles dose	Vaccination registries
Section 2: A social marketer, health promoter and media specialist perspective			
Develop accessible, tailored services	Make vaccination services more accessible to working people – extend hours	Parents accessing services during extended hours	Vaccination/ institutional records
Make not being protected an active decision	Require signed form for vaccination refusal	Signed refusal forms	Immunisation registries

Message	Objective	Indicator	Data Source
Use all media to advocate for the need to be protected and to protect	Make protection dominant framing for vaccination stories	Use of key protection framing words	Media audits. Analyse principal framing messages before and after implementing information intervention
Actively counter misinformation	Increase use of reliable vaccination information websites	Number of visits to websites	Google searches and web utilisation data.
Section 3: A peer perspective			
Keep our immunisation knowledge current	Make continuing medical education materials available on vaccination	Number of HCPs passing CME test	CME enrolment records and score results
Section 4: A so-called “hard-to-reach” population perspective			
Include us in all stages of programmes aimed at enhancing our inclusion and health	Engage representatives of target groups in evaluation process	Number of representatives involved	Meeting records
Health mediators are a critically important resource – they need to be supported	Increase number of health mediators per capita by X%	Number of health mediators	Institutional/ community/ national employee data
Help enhance our health literacy	Increase vaccination knowledge	Scores on vaccination knowledge test	Vaccination knowledge test

Checklists

‘Checklists’ are communication tools that can aid the management of complex or neglected tasks. They are low-cost innovations with an increasingly large evidence base; checklist-based solutions have been shown to reduce complications, save lives and improve institutional and individual behavioural choices and performance. Effective checklists programs bundle vital elements of existing guidelines into simple, user-friendly formats comprised of actionable and/or measureable items. These toolkits identify essential health practices, provide key reminders to complete these practices at crucial periods, and empower providers and other stakeholders to rapidly assess and address gaps in the integrity of their own health and/or health systems (51,52). Table 2 and 3 below present ‘user’ checklists that could be given to parents or representatives of poorly reached/underserved populations to elicit feedback on how well HCPs are following advice given in the guidance.

Table 2: Evaluating HCP behaviours – Parents checklist

Observed behaviours	YES	NO	NOT SURE / Not Applicable
Informed you about the dangers of non-vaccination			
Took time to listen to you			
Told stories as well as sharing scientific facts			
Took account of those who do get immunised			
Appreciated your efforts to find out more			
Took steps to reduce the stress of shots			
Gave you time to decide			
Supported you with follow-up appointments and schedules			
Helped you to know where you could go for more information			

Table 3: Evaluating HCP behaviours – “Hard-to-reach” population feedback checklist

Behaviour	YES	NO	NOT SURE/ Not Applicable
Knows something about your cultural reality			
Sees systems as problem not you			
View immunisations as one part of larger health challenges			
Integrate you into mainstream programmes			
Include you or your representatives in all stages of programmes aimed at enhancing your inclusion and health			
Supports concept of health mediators			
Is accessible and respectful			
Helps enhance your health literacy			



World Health Communication Associates (WHCA)

physicians, nurses, pharmacists, community health workers, mediators