

# Let's talk about protection

Enhancing childhood vaccination uptake



Communication guide for healthcare providers



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This is a revised edition of Let's Talk About Protection: Enhancing childhood vaccination uptake, commissioned by the European Centre for Disease Prevention and Control (ECDC), and produced by World Health Communication Associates Ltd (WHCA) in 2012.

The content has been restructured and streamlined for this new edition. It forms part of a toolkit that aims to support EU/EEA countries in their communication initiatives to increase immunisation uptake, in particular childhood vaccination. Template materials and other resources are available online at <http://ecdc.europa.eu/en/healthtopics/immunisation/Pages/Communication-toolkit.aspx>.

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## Introduction

Welcome to the European Centre for Disease Prevention and Control (ECDC) communication guide on childhood vaccination. It provides practical peer-reviewed advice and evidence-based guidance for healthcare providers who are involved with immunisation services<sup>i</sup> on ways to increase the uptake of childhood vaccinations. This advice and guidance is delivered by giving voice to the thoughts, knowledge and insights of parents, social marketers<sup>ii</sup>, health promoters and other health service and public health experts. The advice aims to help healthcare providers gain insights into the behaviour and choices of different stakeholders and identify ways to better address concerns about vaccination and other obstacles to vaccination uptake.

<sup>i</sup> The term 'healthcare 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).

<sup>ii</sup> Experts in behavioural communication and change.

## The crucial role of healthcare providers

Multiple studies show that in all European Union (EU) countries, healthcare providers 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, who have the most questions and concerns. The personal credibility of healthcare providers and their positions of trust place them in a unique position to help support parents in understanding vaccination and choosing to get their children protected.

## Today's vaccination challenges

As regards vaccination, Europe has some big challenges! Vaccination rates for some preventable diseases in many EU countries have dropped below the recommended coverage rates that are needed to sustain protective 'community immunity'<sup>i</sup>. This has left large pockets of susceptible populations<sup>ii</sup> in many EU countries and diseases that were once well controlled are now reappearing. An outbreak of measles in the western part of Europe was amongst the largest in the world in 2011 [4]; more than 30 000 cases of measles were reported in the EU and countries of the European Free Trade Association. Cases were reported in all countries, except the island nations of Iceland and Cyprus. This is a public health failure. Measles is completely preventable and Europe is committed to its elimination.

Measles is not a harmless disease! It can cause some serious complications, sometimes leading to death. In the western world, 1–3 patients per 1000 will die as the result of a measles infection [5]. The key factor contributing to the European measles epidemic is sub-optimal vaccination uptake and reach that has left large population groups either unprotected 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].

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<sup>i</sup> See 'Vaccines protect everyone' in Section 5.

<sup>ii</sup> Even in countries with high coverage rates the number of unvaccinated people will accumulate over time (ECDC, 2012) and poorly protected pockets of vulnerable people can be found.



## Unprotected and under-protected populations

Recent studies have identified a range of characteristics common to unprotected and under-protected (unimmunised and under-immunised) populations [6,7] In broad terms the following four key population groups<sup>i</sup> have been identified.

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

**'The unconcerned'** – those for whom immunisation is considered a low priority with no real perception of risk from 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.

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

## The focus, aim and approach of this guide

The focus of this guide is on behaviour-related communication. Its aim is to identify ways to help healthcare providers encourage 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 on 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. 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.

<sup>i</sup> In this guide, concerns and advice for healthcare providers 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.

## Capturing insights and advice

Through this process we have gained qualitative insights into different groups' 'vaccination journeys'<sup>i</sup> and importantly, have obtained advice on how those journeys could be made easier. The insights and advice 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 PubMed and Google searches. All these sources were then used to develop the advice we've presented as being given by the different groups. Initial drafts of this advice were amended and redrafted based on reviews and critiques from relevant stakeholders. In this way the guide presents evidence-based and peer-reviewed but simulated conversations between stakeholders and healthcare providers. Three key messages for healthcare providers emerged from this process:

- Make vaccine communication more of a two-way information exchange
- Keep the focus of discussions on the benefits of getting protected and protecting
- Make the settings and systems in which people obtain vaccinations simpler, more accessible and easier to navigate.

## Two-way communication

The people we consulted noted that communication from healthcare providers, often due to time constraints, was generally too focused on one-directional communication and the sending of well-intentioned but uniform messages to all. Healthcare providers 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.

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<sup>i</sup> 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 healthcare systems, consulting with their providers, getting, delaying or refusing to get their children immunised, dealing with side effects, following up with schedules, etc.

## 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 healthcare providers 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 they are protecting them, and the communities in which they live, from serious and potentially deadly diseases.

## Effective design and reconfiguration of services

A need was uniformly reported 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.

## Organisation of the guide

Part I of this guide presents feedback and advice to healthcare providers on ways to improve communication around the issues of vaccination. Advice is presented from the perspective of parents, health promoters, social marketers, peers and representatives of so-called 'hard-to-reach' populations.

Part II provides background information that can be used to support conversations with patients and carers. It also includes a question and answer section on issues of common concern.

The guide forms part of a toolkit that aims to support EU/EEA countries in their communication initiatives to increase immunisation uptake, in particular childhood vaccination. Template materials and other resources are available online at <http://ecdc.europa.eu/en/healthtopics/immunisation/Pages/Communication-toolkit.aspx>.





Photo: ECDC / Tibor Bujdos

## PART I

# PERSPECTIVES

This part of the 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** Perspectives from so-called 'hard-to-reach' populations

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 healthcare providers should consider in their vaccine-related conversations and interventions with all parents and carers.



## **Section 1**

### **A parent (grandparent) and carer perspective**

## Summary messages

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

## Do what you recommend others to do

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

Some of us also worry that if a healthcare 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 to do.

## Teach us about the risks of non-vaccination

We recognise that most of us and you, including the younger (and not so young) generation of healthcare providers, 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.

## 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. Be aware that we want real stories not sensationalism.

### Sample Q&A<sup>7</sup>

#### Number of vaccines

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

**Healthcare 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.

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<sup>i</sup> Sample questions and answers are presented throughout the guide as an aid to provider-parent conversations. They have been adapted from 'Provider Resources for Vaccine Conversations with Parents', developed by the CDC, the American Academy of Family Physicians (AAFP) and the American Academy of Pediatrics (AAP), and available from <http://www.cdc.gov/vaccines/hcp/conversations/index.html>.



## 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 look at 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.

**Healthcare 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.

## **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 on 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!

## **Don't be put off by our efforts to find out more**

Many parents today want to work in partnership with you, our family healthcare 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.

## **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 other locations for delivering vaccines such as schools, community pharmacies or shopping areas.

## 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.

## Help enhance our understanding of vaccinations

Please use language we can understand. Try to avoid using too much technical or medical language and when you do need to use it, 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, with to the addresses of 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 suitability 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, text messages (SMS), or email reminders.

Being well informed about the dangers of vaccine-preventable diseases and the importance of protective vaccination empowers<sup>i</sup> 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.

<sup>i</sup> For a definition of 'Empowerment for health', see the World Health Organization's Health Promotion Glossary. (1998) Available from [http://whqlibdoc.who.int/hq/1998/WHO\\_HPR\\_HEP\\_98.1.pdf](http://whqlibdoc.who.int/hq/1998/WHO_HPR_HEP_98.1.pdf)





## **Section 2**

### **A social marketer, health promoter and media specialist perspective**

## Summary messages

- **Focus on behaviour and its determinants - not just the message**
- **Develop accessible, friendly and adapted places for vaccination services**
- **Make the discussion about 'being protected' rather than about vaccine safety**
- **Make those who accept vaccination more visible – build on and reinforce vaccination as a social norm**
- **Show that being unprotected is socially unacceptable**
- **Ensure any decision to remain unprotected is an active one**
- **Use all media to advocate for the need to be protected and to protect**
- **Actively counter misinformation**
- **Guide patients to reliable sources of information**

## Focus on behaviour and its determinants – not just the message

Health information in isolation is rarely enough to achieve sustained positive health behaviour. The reasons why people decide to be vaccinated 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<sup>i</sup>) of the people you are trying to help. Avoid making assumptions about different groups of people and always check that your understanding of their situation or circumstances is correct by discussing this with them.

Interventions delivered by the healthcare provider for individuals can involve simple advice, discussion, negotiation or encouragement. On an institutional and community level, providers can advocate for policies and procedures that help make protective vaccination an easier choice; for example, make locations and delivery systems for vaccination more affordable, accessible and easier to navigate.

<sup>i</sup> See, further, New South Wales Department of Health (2010), Public Health Classifications Project – Determinants of Health Phase Two: Final Report. Australia. Available from <http://www.health.nsw.gov.au/hsnsw/Publications/classifications-project.pdf>

## **Develop accessible, friendly and adapted places for vaccination services**

It is particularly important that the places in which vaccination 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 providers expect people to visit them. While this can be done, ways should also be considered of taking services out to where people already 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 towards increasing uptake.

## **Reframe the discussion so that the main focus is on being protected, rather than on vaccine safety**

Framing strategies<sup>i</sup> 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 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 policymakers. Reframing strategies are key. Much of the success of anti-vaccination lobby, for example, is attributable 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 the real but small safety risks into 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

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<sup>i</sup> 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 p 362 [12]).

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. [9-11].

### 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.

**Healthcare provider:** I'll worry if your child doesn't get vaccines today, because the diseases can be very dangerous. Measles, pertussis and *Haemophilus influenzae* type b, 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.

**Healthcare 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 the diseases is far greater than any risks posed by vaccines. Vaccines will get your baby off to a great start, protected for a long, healthy life.

## 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.

## **Show that being unprotected is socially unacceptable**

It can also be useful to look at ways to reinforce the message that it is socially unacceptable to remain unprotected and increase risks for others. Attention might be focused (for example through parent surveys) on whether particular groups (such as teachers, nurses, doctors, social workers, etc.) who come into contact with a lot of people should be protected by immunisation as a socially responsible action in their work. Building this issue as an important one can then help people 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, childcare settings and institutions.

## **Ensure any decision to remain unprotected is an active one**

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. in the US, some general practitioners ask 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.



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

The traditional and social 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<sup>i</sup> 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 ongoing relationship [13].

## Actively counter misinformation

Anti-vaccination forces use blogs and social media very effectively to spread fear and concern about vaccine safety and often, these stories go unanswered. However, the UK's National Health Service actively counters 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<sup>ii</sup> 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 vaccine confidence website<sup>iii</sup> also provides regular updates on news related to vaccine confidence.

<sup>i</sup> 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.

<sup>ii</sup> [www.nhs.uk/news/pages/newsindex.aspx](http://www.nhs.uk/news/pages/newsindex.aspx)

<sup>iii</sup> [www.vaccineconfidence.org](http://www.vaccineconfidence.org)



## Guide patients to reliable sources of information

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.

The ECDC Communication Toolkit<sup>i</sup> contains the template for a leaflet on 'Evaluating Internet sources of immunisation information' which can be useful to share with patients.

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<sup>i</sup> [www.ecdc.europa.eu/en/healthtopics/immunisation/Pages/Communication-toolkit.aspx](http://www.ecdc.europa.eu/en/healthtopics/immunisation/Pages/Communication-toolkit.aspx)



Photo: ECDC / Tibor Bujdos

## Section 3

### A vaccination expert and provider (peer) perspective

## Summary messages

- **Keep your immunisation knowledge current**
- **Strengthen your communication skills**
- **Use the team and other settings to provide information and address concerns**
- **Maintain your skills to ensure safe vaccine administration**

## Keep your immunisation knowledge current

Studies show that healthcare 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, they 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 [14]. Providers must critically appraise promotional materials received from pharmaceutical company representatives.

## 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 with parents that sensitively address their concerns and patiently answer their questions. Many have found the logical CASE approach to conversation<sup>i</sup> useful (see Box 1).

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<sup>i</sup> Developed by Alison Singer, founder of the Autism Science Foundation.

**Box 1****The CASE approach**

- C**orroborate: Acknowledge the patient's concern and find some point on which you can agree. This sets the right tone.
- A**bout Me: Describe what you have done to build your knowledge base and expertise.
- S**cience: Describe what the science says.
- E**xplain/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 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 2), you can communicate and use your time more effectively.

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

*(Adapted from: Wellington-Dufferin-Guelph Public Health. Educate. Protect. Vaccinate. A resource to address parents' concerns about childhood vaccines. Canada; 2007)*

### 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.

### 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.

**Box 2**
**Addressing the hesitant, unconcerned, resistant and poorly reached:  
Discussion tips**

Category	Characteristics	Chance of positive outcome (immunisation)
<b>The Hesitant</b>		
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.
<b>The Unconcerned</b>		
Uninformed	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.
<b>Active Resisters</b>		
Convinced and content	Convinced that immunisation is bad and content with the decision not to immunise. In your office because someone has nagged 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.
<b>Poorly Reached</b>		
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. are inconvenient	Extended hours or alternative locations can help address this group.

**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.

## **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 available in waiting rooms with information brochures and posters. Some provide information evenings for parents or organise sessions to inform future parents when they visit midwives and obstetricians.

## **Maintain your skills to 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 healthcare providers self-assess their competencies and seek training for weak areas (see Box 3).

Below is a self-assessment tool for healthcare 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.



**Box 3**

**Skills checklist for protective immunisation: Healthcare provider self-assessment**

*(Reproduced with permission from the California Department of Health Services – Immunization Branch.)*

Competency	Self-assessment	
	Need to improve	Meets or exceeds
<b>Clinical skills, techniques and procedures</b>		
<b>A. Patient/Parent education</b>		
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.		
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 aftercare instructions with patient/parents, inviting questions.		
<b>B. Medical protocols</b>		
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.		
<b>C. Vaccine handling</b>		
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); 5/8" for SC (MMR, Var); IPV and Pneumo Poly depends on route to be used.		
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.  |  |  |
| 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.  |  |  |

### 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 up patient 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 immunisation 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 healthcare customer satisfaction or cultural competency training.
- m. Renew CPR certification.

Other:



Photo: ECDC / Tibor Bujdos

## Section 4

# Perspectives from so-called 'hard-to-reach' populations

- Introduction
- Socially disadvantaged groups
- Anthroposophists

## Introduction

For the purposes of this guide, so-called 'hard-to-reach' populations (see reframing discussion, 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 people from the following groups: Roma communities; Traveller communities; anthroposophist; ultra-orthodox Jewish communities; Christian reformed churches; other reformists and radical groups.

## Socially disadvantaged groups

### 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 because of their 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 [15]. 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 healthcare 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 4). Roma comprise many different subgroups with diverse culture and traditions and all groups have their own individual beliefs and customs [16]. Countries with the highest percentage of Roma people in the EU include Bulgaria, Romania, Czech Republic, Slovakia, Hungary, Spain and Greece.

**Box 4****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 or behavioural factors include: negative attitudes and mistrust (bi-directional) between the Roma communities and public institutions; negative perceptions of, and attitudes towards, Roma by healthcare staff; low levels of 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 healthcare providers and lack of target-specific information materials in healthcare facilities and by healthcare providers; stigma and discrimination [17].

**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 to 300 000 [16]. UK studies show that access to healthcare services is difficult because of Travellers' lack of permanent addresses.

## Advice from their perspective

### Summary messages

- Know more about us
- Reframe 'hard-to-reach' as mainly 'poorly reached' system failures
- View immunisation as one part of a larger health challenge
- Integrate us into mainstream programmes
- Involve us in all stages of programmes aimed at improving our inclusion and health
- Adapt governance and healthcare systems to be more inclusive
- Health mediators and other community health workers are a critically important resource for us – they need to be supported
- Be accessible and respectful
- Beware of incentives that could be viewed as bribes for compliance

### Know more about us<sup>i</sup>

Healthcare providers who work with us should have background knowledge of our culture and the perceptions we have with regards to health; information regarding our health status; insight into the internal diversity of our communities; and awareness of the strengths and weaknesses of prior intervention experiences (e.g. see Box 5 with information on Roma attitudes, beliefs and values).

### Roma health – attitudes, beliefs and values in brief<sup>ii</sup>

#### Our perception of health

For many of us, health is not perceived as a top priority. Housing, finances and 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

<sup>i</sup> The voices and messages expressed in the text are based in some instances on translations from the respondents' own language.

<sup>ii</sup> Some terms such as 'For many of us health is not perceived as a top priority' may not be reflective of the whole community.

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. [18]

### **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 organisation**

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 healthcare system but rather between the individual who is ill, the extended family and the healthcare 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 people, 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 healthcare 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.<sup>i</sup>

### **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 people. Too often, healthcare 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 Box 6). Addressing obstacles to our protective vaccination uptake requires attention not only to our behaviour 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 us and fear of us (Cotter, 2012, personal communication).

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<sup>i</sup> Some of the phrases used such as 'mutual distrust' and 'mutual prejudice' fail to acknowledge the power dynamic and the statutory duty of a service provider and their mandates to treat all people equally (Maria Daly and Siobhan Curran, Pavee Point Traveller and Roma Centre, Dublin, 2012, personal communication).



**Box 5****Determinants of socially disadvantaged populations' exposure, vulnerability, access to, and consequences of, care related to communicable diseases [17]**

Increased exposure	<p>Some socially disadvantaged groups are more likely to be exposed to communicable disease because they have:</p> <ul style="list-style-type: none"> <li>■ less access to improved water sources</li> <li>■ inadequate and over-crowded living conditions with poorly ventilated housing</li> <li>■ poor herd immunity for vaccine-preventable diseases in their immediate community</li> <li>■ more exposure to sick family members or other contacts who have delayed treatment</li> </ul>
Increased vulnerability	<p>Once exposed to an infectious agent, some socially disadvantaged groups are more likely to become infected because of:</p> <ul style="list-style-type: none"> <li>■ underlying malnutrition (micronutrient deficiencies, underweight, and in some contexts, overweight)</li> <li>■ underlying illness</li> <li>■ unvaccinated or incomplete vaccination</li> <li>■ less access to other (non-vaccine) preventive measures</li> </ul>
Poorer access to quality services	<p>Once they are sick, socially disadvantaged groups generally have poorer access to quality healthcare services because of:</p> <ul style="list-style-type: none"> <li>■ discrimination or culturally incompetent care</li> <li>■ being more likely to avoid seeking care due to having experienced or heard about discrimination in healthcare settings</li> <li>■ living far from a health centre</li> <li>■ the lack of health insurance or other requirements for accessing care</li> <li>■ cost<sup>i</sup></li> <li>■ not being able to purchase prescribed medicines</li> <li>■ problems in adhering to certain treatments, such as those for particularly stigmatised illnesses or those that are expensive to treat</li> <li>■ misunderstanding of prescribed treatment due to low education/literacy levels</li> </ul>
Worse consequences of contact with health system	<p>Utilising health services may entail worse consequences for socially disadvantaged groups because:</p> <ul style="list-style-type: none"> <li>■ Catastrophic expenses can lead to further impoverishment and decreased demand for healthcare in the future</li> </ul>

<sup>i</sup> 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).

### **View immunisation as one part of a larger health challenge**

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<sup>i</sup> and support sustained inclusion solutions: e.g. resource building – healthcare provider 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 as those needed to address many of the broader challenges our populations face.

### **Integrate us into mainstream programmes**

Supplemental protective vaccination programmes 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 them. The information we need most of the time is the same as the rest of the population. Universal information and education materials should be developed for the entire population and then adapted, as required, to create culturally appropriate and inclusive services and support that address specific groups with their own characteristics. Adaptation should include asking us about our needs and perceptions.

### **Involve us in all stages of programmes aimed at improving 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

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<sup>i</sup> 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. [18]

implementation. In particular, peer-to-peer activities complemented with the involvement of local social workers, teachers, assistants and mediators, have been shown to be helpful.

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

### **Adapt governance and healthcare 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.<sup>i</sup> We are refused access to GP and primary care services, for example, on the basis that we do not have a valid medical card, 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 strengthen our health literacy. Moreover, services can be supplemented with home visits from doctors, the use of mobile teams and community nurses. Further, school settings can be used as platforms for health promotion, and stronger involvement of local NGOs, including faith-based workers and other actors in the vaccination process can also improve systems.

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

<sup>i</sup> Recent legislation 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).

### **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 to increase vaccination rates, obtain identification and insurance documents and provided us and our children with health education. 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 within healthcare 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 others losing interest (other professionals in the healthcare system, 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 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 healthcare providers who are usually women from the community. They provide a lot of peer-to-peer education and encouragement on health-related matters.<sup>i</sup>

### **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 healthcare services. It is, therefore, essential that you pay particular attention to these aspects, especially when a relationship is first being established with members of socially isolated communities. Always remember that different does not mean problematic or vaccine-refusing. Be prepared to invest time in building relationships. Unfortunately we have too often found that healthcare 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

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<sup>i</sup> Primary healthcare projects for Travellers are active in 30 areas across the country and work to raise awareness, disseminate information, and promote vaccination (see <http://paveepoint.ie>).

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.

### **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 behaviour. 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.

## **Anthroposophists**

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'. 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 anthroposophical concepts of education, with approximately 700 in Europe. There is a current debate on measles vaccination amongst anthroposophical physicians in some countries, e.g. Germany [16].

### **Advice from their<sup>i</sup> perspective**

#### **Summary messages**

- **Understand us better**
- **Listen to our concerns – give us time**

<sup>i</sup> Many thanks to Nelly Fournet and Liesbeth Mollema for sharing work in progress in this area.



### **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.

### **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.

## **Some people within particular religious communities**

Ultra-orthodox Jewish communities (particularly in Israel, the UK, France and Belgium) 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 [19].

## **Other reformist and radical resistant groups**

In addition to some of the socially excluded and religious groups resistant to vaccination described above, Hobson-West [20] identifies a variety of reformist and 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 behaviour, 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.



## PART II

# SUPPORT MATERIAL FOR CONVERSATIONS WITH PARENTS AND CAREGIVERS

This part of the guide provides you, as healthcare providers, with background information that can be used to support your conversations about vaccination with families, community leaders and the media.

Section 5 contains some facts about vaccination that can help you make the case for protection. Section 6 is a compilation of commonly asked questions with suggested answers that can be used to assist with conversations with patients, or made into information sheets to inform patients ahead of their visit.

In addition to the information presented in this guide, further resources are available online<sup>i</sup>.

<sup>i</sup> <http://ecdc.europa.eu/en/healthtopics/immunisation/pages/index.aspx>



## Section 5

# Making the case for protection

- Vaccines reduce suffering and save lives: a public health success story
- Vaccines are safe and effective: the diseases they prevent can cause permanent disability or even death
- Vaccines protect everyone
- Vaccine safety licensing in the EU
- When vaccination rates decline, rates of disease increase



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

'Over half of the (30%) drop in child mortality since 1990 is attributable to immunization.'  
 Dr Margaret Chan, Director-General, World Health Organization

Vaccines are our best defence against infections that may have serious complications such as pneumonia, meningitis, cancer, and even death. Due to vaccinations, we no longer see smallpox, and polio has almost been eradicated.

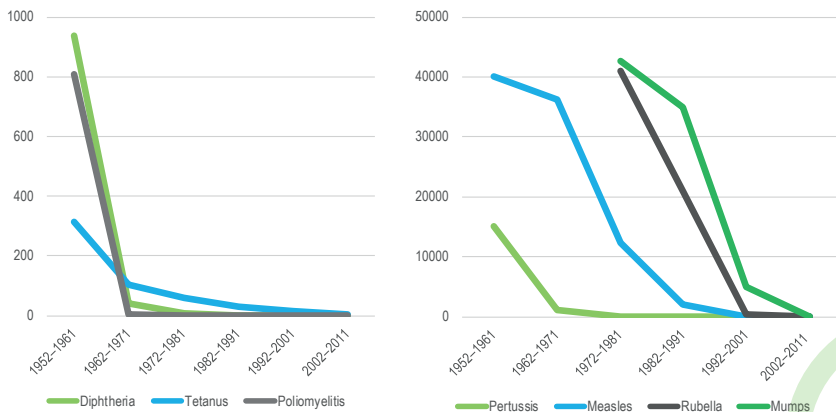
Smallpox was the first disease to disappear because of vaccination. There have been no cases of smallpox anywhere in the world since 1979. Children are no longer vaccinated against smallpox.

Paralytic polio has been eliminated from most of the world through vaccination. In 2015, polio remained prevalent in only two countries: Afghanistan and Pakistan. 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.

The diseases that children are vaccinated against may be rare now, but if children aren't vaccinated, they can return with a vengeance.

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

### Average number of cases per year from some vaccine preventable diseases (example – Hungary 1952–2011)



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

Some people are concerned that vaccines carry an unnecessary risk. The table below compares the consequences of contracting each disease with the possible side effects of the respective vaccine. In each case, the benefits of vaccination (i.e. avoiding the symptoms of the diseases) far outweigh the risks associated with the vaccines.

Disease	Symptoms/effects of the disease	Possible side effects of the 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, if any, to be measured.
Polio	Muscle paralysis in 1 out of 200 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).
Measles	Severe bronchitis, high fever, rash for 7–14 days; death in 1 per 1000 cases; encephalitis in 1 per 1000 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 24000 develops low platelets.
Mumps	Fever, swollen salivary glands. No visible illness in > 50% of cases. Encephalitis in 0.02–0.3% of cases; deafness in 5 per 100000 cases. [21]	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.	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.
Pneumococcus	Severe infections result in the death of approximately 30% of infected children; 15–20% of survivors of meningitis have brain damage, deafness.	Minor local redness, swelling and pain in 15% of recipients.
Varicella	Hospitalisation in 1000 and death in 10 cases per year due to pneumonia, encephalitis, severe skin infections; shingles (zoster) later in life.	Minor local reaction; rash in about 5% of children.
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 hepatitis B infection. [22]	Minor local redness, swelling and pain.
Meningococcus	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. Death in children under 5 years old is extremely rare but 1.5% of infected people aged over 60 may die [23].	Mild pain and redness at injection site.
Human papillomavirus (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 [22].	Mild pain and redness at injection site.
Rotavirus	Death from severe dehydration caused by profuse, watery diarrhoea. Potentially fatal diarrhoea occurs in about 1 in every 75 cases [22, 23] Globally, more than two million children are hospitalised for rotavirus infections every year [24].	A slight increase of intussusception has been reported; a rare but quite serious effect. No other significant reactions.

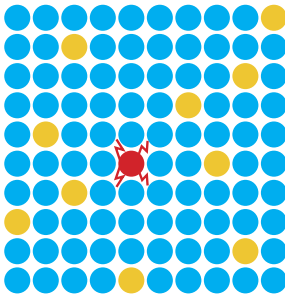
Source: Adapted from Canadian Paediatric Society (2010). *First Shots. Best Shot: Childhood vaccines at work in Canada* [PowerPoint presentation based on 'Your Child's Best Shot: A parent's guide to vaccination (3rd edition, 2006)']. Available from <http://resources.cpha.ca/immunize.ca/data/1770e.ppt>

## Vaccines protect everyone

This information is available as a leaflet 'What is community immunity?' as part of the ECDC Communication Toolkit<sup>i</sup>.

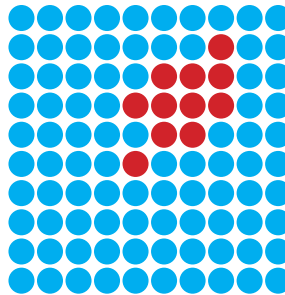
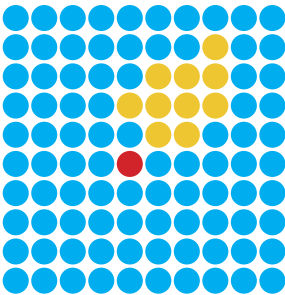
### Community immunity

Vaccination protects you and your family, and it also helps protect others. It contributes to 'community immunity'. This is achieved when enough people in a population are immune to an infectious disease (through vaccination and/or prior illness) so that it is unlikely to spread from person to person. Even those who cannot be vaccinated because they are too young, are allergic to vaccine components, or vaccination is contraindicated for them, are offered some protection because the disease cannot spread in the community and infect them. This is also known as 'herd immunity'.



When enough people are protected (blue dots) in a community they can protect those who are not yet vaccinated (yellow dots) from those who are infectious (red dots).

When groups of unvaccinated people build up and are in close proximity, community immunity doesn't work and the disease spreads.



<sup>i</sup> [ecdc.europa.eu/en/healthtopics/immunisation/Pages/Communication-toolkit.aspx](https://ecdc.europa.eu/en/healthtopics/immunisation/Pages/Communication-toolkit.aspx)

## Vaccine safety licensing in the EU

Before a new vaccine is approved and marketed in the EU, a rigorous regulatory procedure that assesses quality, efficacy and safety must be followed.

All vaccines have to obtain a 'marketing authorisation' before they can be sold. This is only granted after an evaluation of the data collected during product development and clinical trials. Compliance with good practice in the areas of manufacturing and clinical or laboratory testing is also verified by regulatory agencies prior to approval of a marketing authorisation.

There are several different procedures in Europe to register or licence a new vaccine: a centralised procedure which is undertaken at EU level by the European Medicines Agency<sup>i</sup> and applies in all Member States; a procedure based on 'mutual recognition' between certain Member States that applies only in those countries; and national procedures for products that are only licensed for use in that one country.

Once a marketing authorisation is obtained, each batch of vaccines must still be assessed for quality before release for use. This is done by both the manufacturer and an official European control laboratory.

In addition, after release onto the market, all vaccines are monitored for adverse events following immunisation. Suspected adverse events are reported by vaccinators or the general public to the National Regulatory Agencies in all countries and in some countries simultaneously to the national public health institutes. The reporting obligations of the various stakeholders are defined in national laws and in the European legislation.

All reported suspected adverse events are collected and regularly evaluated in the large European Eudravigilance database<sup>ii</sup> hosted by the European Medicines Agency. Should a safety signal be detected, epidemiological studies are initiated to confirm or refute a safety signal.

Vaccines have to meet additional requirements after licensing, including follow-up measures like stability studies, further confirmatory trials or trials in populations that have not yet been studied. Under EU legislation, licences also have to be renewed five years after approval.

<sup>i</sup> [www.ema.europa.eu](http://www.ema.europa.eu)

<sup>ii</sup> <https://eudravigilance.ema.europa.eu>



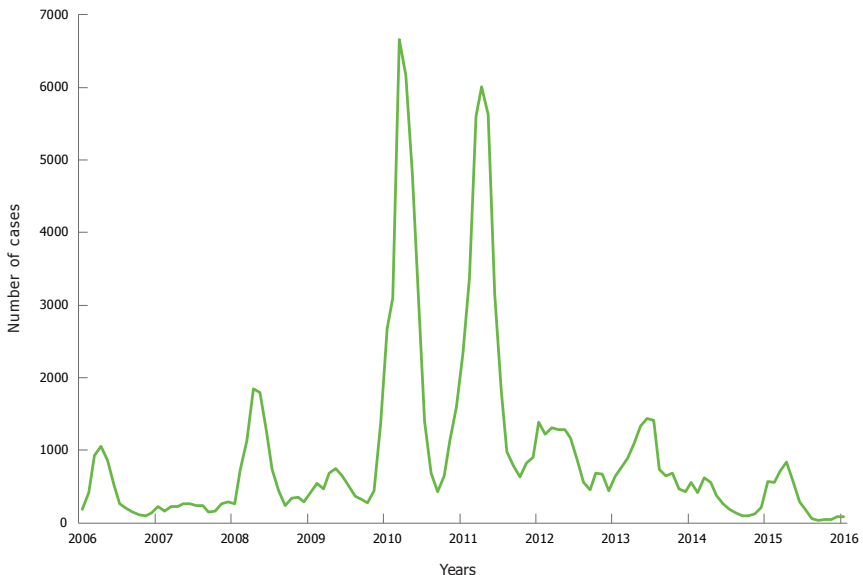
## When vaccination rates decline, rates of disease increase

Diphtheria in the 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 consequently 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 programme eventually controlled the epidemic.

In the 1970s, bad publicity in Japan about the pertussis vaccine caused people to stop using it. In the three years before the vaccine was stopped the country had 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 the early 1980s.

Sub-optimal uptake of MMR vaccine in many EU countries and accumulation of unvaccinated children has resulted in measles outbreaks in Europe.

### Number of measles cases by month in the EU, January 2006 – September 2014



Data from 29 countries for 2006–2011; 30 countries for 2012–2014



## Section 6

### Questions and answers

- General
- Pre-vaccination: Should my child get immunised today?
- Delaying vaccination
- Autism
- Vaccine ingredients

This section contains some commonly asked questions with suggested answers that can be used to assist with conversations with patients, parents or caregivers, or made into information sheets be shared with them ahead of their visit. They have been adapted from information sheets developed by the HSE National Immunisation Office, Ireland [25], the Children’s Hospital of Philadelphia, US ([www.chop.edu](http://www.chop.edu)) and Wellington-Dufferin-Guelph Public Health, Canada [26].

## General

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.** *How do vaccines work?*

**A.** Vaccines contain either a very weakened form of the virus or bacterium that causes a disease, or a small part of it. When the body detects the contents of the vaccine, its immune system will produce the antibodies required to fight off infection and eliminate the disease-causing virus or bacterium.

When a person later comes into contact with the virus or bacterium, the immune system will recognise it and protect the person by producing the right antibodies before any disease can be caused.

**Q.** *Are children receiving too many vaccines too soon?*

**A. No. Newborns commonly manage many challenges to their immune systems at the same time.** The mother's womb is free from bacteria and viruses, so newborns 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 drop in the ocean of what an infant's immune system successfully encounters and manages every day [27].



## Pre-vaccination: 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 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 delay their MMR vaccination.

**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. Only children that develop allergic shock when in contact with egg should avoid the MMR vaccination. Your child simply disliking eggs or having diarrhoea or stomach pains after eating eggs is not a reason to avoid it, and you do not need to take any special precautions. If you have any doubts, talk to the doctor or nurse giving the immunisation.

The 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 fits 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 influenzae, 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 A.

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

## Delaying vaccination

**Q.** *Is it ok to delay vaccination?*

**A.** No evidence to date reveals any benefits to delaying vaccines. A study in 2010 [28] showed that children who received delayed vaccinations performed no better at ages seven to 10 on behavioural and cognitive assessments than children who received their vaccines on time. 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 very common and may severely affect very young children. Although the vaccine schedule can look intimidating, it is based upon the best scientific information available.

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.

## Autism

Some parents of children with autism are concerned that vaccines are the cause. Their concerns centre on the combination measles-mumps-rubella (MMR) vaccine and thiomersal, a mercury-containing preservative previously contained in several vaccines.

**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 [29,30].

**Q.** *Does thiomersal cause autism?*

**A.** No. Multiple studies have shown that thiomersal in vaccines does not cause autism. Thiomersal is a mercury-containing preservative that was used in vaccines to prevent contamination. In 1999, professional groups called for thiomersal to be removed from vaccines as a precaution. Unfortunately, the precipitous removal of thiomersal from all but some multi-dose preparations of influenza vaccine scared some parents. Clinicians were also confused by the recommendation. Since the removal of thiomersal, studies have been performed to determine whether thiomersal causes autism. Hundreds of thousands of children who received thiomersal -containing vaccines were compared to hundreds of thousands of children who received the same vaccines free of thiomersal. The results were clear: the risk of autism was the same in both groups [31-34].

## 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.

**Q.** *Why do some vaccines contain mercury?*

**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 thiomersal, a mercury-containing compound. As more vaccines were given, children received greater quantities of thiomersal. 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 thiomersal 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 thiomersal 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.

**Q.** *Why do some vaccines contain antibiotics?*

**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.

**Q.** *Why do some vaccines contain aluminium?*

**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 [35].

**Q.** *Why do some vaccines contain gelatin?*

**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 the amount 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 [36].

**Q.** *Why do some vaccines contain formaldehyde?*

**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 the formaldehyde is diluted during the manufacturing process, 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 [37].

**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 [38].

**Q.** *Can the ingredients in vaccines cause allergic reactions?*

**A.** **In addition to gelatin, other ingredients in vaccines such as egg proteins and antibiotics 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 cause an allergic reaction, albeit rarely, in people allergic to eggs.

Antibiotics are used to prevent bacterial contamination during production of some vaccines, such as neomycin, streptomycin, polymyxin B, chlortetracycline and amphotericin B. People who are allergic to any of the antibiotics used during production should consult with the doctor or nurse responsible for the immunisation before any vaccine is administered.



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# Annex 1

## Methodology and approach

This describes the methodology used to develop the original *Let's Talk About Protection* guide, on which this current edition is based.

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

### 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 PubMed 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.

ECDC technical studies and documents included:

- A literature review on health information-seeking behaviour on the web: a health consumer and health professional perspective [39].
- A literature review of trust and reputation management in communicable disease public health [40].
- Conducting health communication activities on MMR vaccination [41].
- Summaries of studies in process related to risk communication and immunisation web page analysis.

Selected peer-reviewed and 'grey literature' sources were identified through PubMed and Google searches. Keywords for PubMed searches included 'childhood immunisation', 'vaccination advice' and 'vaccine 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. 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.

**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 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 contacts from the World Health Editor's Network and World Health Youth Journalist 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 people who had direct experience of seeking and obtaining vaccinations for their children (or assisted others to do so) 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 healthcare providers gleaned from the different stakeholders were then compared with advice and guidance offered to healthcare providers in reviewed journal articles and selected websites. Key topic areas were identified and used to develop a first draft of what became Part I of this guide.

## **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 healthcare providers.



## Healthcare provider review

Fifteen selected healthcare 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.

## 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

This list includes the content developers, advisors, expert interviewees and reviewers of the original *Let's Talk about Protection* guide, on which this current edition is based.

### 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 (R)

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 (R) and Media responders (M)

Dr Alex Apfel, Senior House Officer, Frenchay Hospital North Bristol NHS Trust, UK (R)

Ms Sarah Bridgman, Health Visitor, North Somerset Community Partnership, UK (R)

Mr Robb Butler, WHO Regional Office for Europe, Denmark (I)

Dr Hana Cabrnocová, Chairperson Society for primary paediatric care ČLS JEP, Czech Republic (I)

Ms Jill Caughley, RN, MSc Red Cross Primary Care, Geneva, Switzerland (R)

Dr Anna Clarke, Consultant in Public Health Medicine working in Department of Public Health, Ireland (R)

Dr Suzanne Cotter, Specialist in Public Health Medicine, HSE - Health Protection Surveillance Centre, Ireland (I) and (R)

Ms Siobhan Curran, Pavee Point Traveller and Roma Centre, Ireland (R)

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Dr Tarik Derrough, Expert Vaccine Preventable Diseases Response and Support Section - Surveillance and Response Support Unit, ECDC (I)

Ms Maria Daly, Pavee Point Traveller and Roma Centre, Ireland (R)

Dr Irina Dinca, Senior Expert Communicable Diseases Public Health Development section Public Health Capacity and Communication Unit (PHC), ECDC (R)

Dr Bruce Gellin, Head of National Vaccination Programmes, Washington DC, USA (I)

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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)

Mr Martin Kasarda, Media contact, Slovakia (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, Wrington-Vale Practice, Churchill, UK (R)

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). ECDC(R)

Ms. Ger O'Connor, Immunisations Community Services Dublin West Cherry Orchard Hospital, Ireland (R)

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 (R)

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 Tsoleva, Expert in Monitoring and Surveillance, Public Health Development Section, ECDC (R)

Mr Franz Wagner Chief Executive Officer, Director WHO Collaborating Center, German Nurses Association, Germany (R)

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(R)

Dr Piotr Wysocki, Seconded National Expert, Public Health Development, Public Health Capacity and Communication Unit, ECDC (R)

Mrs Sara Zinn, Health Visitor, North Somerset Community Partnership, UK (R)

## 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. post graduate 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, what 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?





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