

# Let's talk about hesitancy

Enhancing confidence in vaccination and uptake



Practical guide for public health programme managers and communicators



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## Introduction

This European Centre for Disease Prevention and Control (ECDC) *Let's talk about hesitancy* guide provides practical evidence-based and peer-reviewed advice for public health programme managers (PHPMs) and communicators involved with immunisation services. It identifies ways to enhance people's confidence in vaccination and addresses common issues which underlie vaccination hesitancy. PHPMs are the target audience for this guide, as they are uniquely positioned to initiate, coordinate and monitor the comprehensive system-wide action needed to address the many psychosocial determinants of hesitancy and provide support to healthcare providers in their efforts to enhance vaccination confidence and uptake. This guide serves as a supplement to the ECDC guide *Let's talk about protection* [1], which focuses on strengthening the capacities of healthcare providers to better address concerns about vaccination and tackle obstacles to vaccination uptake<sup>1</sup>.

i Advice for healthcare providers in Let's talk about protection, is presented from the perspective of parents, health promoters, social marketers, peers and representatives of so called 'hard-to-reach' populations. Sample questions and answers to common concerns are provided throughout the text.

Vaccine hesitancy is defined here as 'a behaviour, influenced by a number of factors including issues of confidence (e.g. low level of trust in vaccine or provider), complacency (e.g. negative perceptions of the need for, or value of, vaccines], and convenience (e.g. lack of easy access). Vaccine-hesitant individuals are a heterogeneous group that holds varying degrees of indecision about specific vaccines or vaccination in general. Vaccine-hesitant individuals *may accept* all vaccines *but remain concerned* about vaccines, some may refuse or delay some vaccines, but accept others; some individuals may refuse all vaccines'. [2]

## **Background studies**

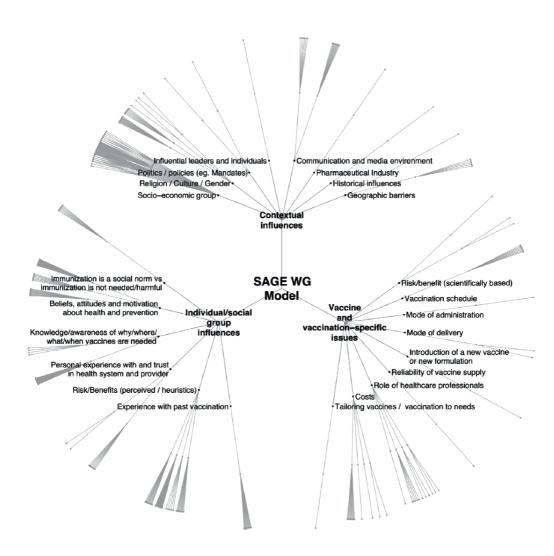
The advice and guidance presented here are based on two ECDC commissioned studies. The first was a rapid review of peer-reviewed and grey literature on vaccine hesitancy performed by the Vaccine Confidence Project of the London School of Hygiene and Tropical Medicine (LSHTM) [3]. The second was a qualitative study designed and analysed by the LSHTM group and carried out with healthcare providers and parents by designated national coordinators in four countries: Croatia, France, Greece and Romania [4]. An expert advisory group as well as staff from World Health Communication Associates (WHCA) and ECDC reviewed drafts.

## **Determinants of vaccination hesitancy**

The ECDC-commissioned literature review and qualitative study (see discussions below) identified a wide variety of determinants of vaccine hesitancy. The term 'determinants of vaccination hesitancy' includes concepts related to barriers and enablers for uptake, reasons for vaccine refusal, beliefs and attitudes towards vaccination and system design mediated factors. These determinants can be usefully categorised<sup>i</sup> as contextual, individual and group influences and vaccine and vaccination-specific issues (see Figure 1 and Table 1).

i This review has adopted the conceptual framework developed by the WHO Strategic Advisory Group of Experts (SAGE) working group as a way of grouping and classifying 'determinants'.

Figure 1
The SAGE Working Group 'Model of determinants of vaccine hesitancy'



Source: Reprinted from Larson HJ, Jarrett C, Eckersberger E, Smith D, Paterson P. Understanding vaccine hesitancy around vaccines and vaccination from a global perspective: A systematic review of published literature, 2007–2012. Vaccine 2014, 32: 2150-2159 with permission from Elsevier.



#### **Contextual influences**

These include the historic, social, cultural, environmental, economic, political and institutional factors which might influence vaccine hesitant populations. The most common 'contextual influence' reported in the ECDC-supported review was conspiracy theories, which include a fear that vaccines are introduced to serve the economic and/or political interests of pharmaceutical companies, western countries, governments, and a belief that vaccines are implemented as a strategy to reduce world population. Religious fatalism was also reported and included beliefs that 'God's decisions are to be trusted' or that humans are created as they should be and that vaccines are not needed. Other articles mentioned negative exposure to the media as a determinant of hesitancy. This includes hearing, reading or seeing negative rumours and myths about vaccines in the general media. The perception that vaccines are being forced upon the population and violate human rights was also reported as a determinant.

#### Individual and group influences

These include personal perceptions of, or beliefs about, vaccines and influences from the social environment. The most common determinant of non-vaccination was the belief that vaccines are unsafe. More specifically, that they can cause severe diseases and side effects, that their long-term effects are unknown, that risks outweigh benefits, and that they contain dangerous adjuvants. Also noted was a lack of information and knowledge about either the vaccine or the disease, which sometimes led to misperceptions about vaccination or targeted diseases. The belief that there is a very low risk of getting the disease or suffering severely from its symptoms was also frequently reported. Perceptions that the vaccine is not effective and does not prevent the disease were also repeatedly noted, as were a general mistrust in institutions, and more specifically in the provision of health services and health systems. Mistrust of healthcare providers was infrequently reported. Some reviews expressed the belief that individuals are healthy enough and that their immune system is strong enough not to require vaccination. Social norms and pressure from friends and family was also reported as a determinant of hesitancy, as was not prioritising vaccination. Social norm influences include discussions and informal talks with friends, family members, peers, co-workers or community members.

Some articles found that hesitant populations can be against vaccination in general. The belief that vaccination is not natural and an expressed preference for alternative prevention methods such as homeopathy was noted, as was the view that childhood infectious diseases can be beneficial for building immune resistance and should therefore not be prevented. Fear of injection and having had a negative previous experience with vaccines (personal or from friends and family) was also a factor identified. The fear and belief that children's bodies are not strong enough to cope with any adverse effects of vaccines was mentioned, as was a feeling of responsibility if something were to happen to children after vaccination.

#### Vaccine- and vaccination-specific issues

Some individuals did not perceive a medical need for certain vaccines. The problem of access (timing or availability of vaccines) and financial cost was encountered several times. A lack of recommendation or inconsistent advice from healthcare providers was noted in several studies. Some studies focussed on refusals in response to the novelty of the vaccine and a consequent fear of insufficient testing and knowledge.

Table 1 identifies all the determinants of vaccination hesitancy retrieved by the ECDC-commissioned literature review, and provides the number of times each one appears in the articles reviewed. This quantification method was found to be a convenient, although a statistically limited, way of obtaining a broader picture of the range and importance of determinants of vaccine hesitancy in the European literature.



Table 1
Determinants of vaccine hesitancy by category and number of times recorded

	Determinant	Number of times recorded*	References
Contextual Influences	Conspiracy theories	7	11, 12
	Religious fatalism	5	12, 13, 14, 15, 16
	Negative exposure to media	3	2, 17, 18
	Violation of human rights	3	11, 12
Individual and group influences	Vaccine safety	31	6, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31
	Lack of information	12	2, 6, 11, 18, 20, 25, 26, 29, 30, 32
	Low risk/severity of disease	10	13, 17, 22, 25, 28, 31, 32
	Vaccines not effective	10	16, 17, 21, 22, 26, 27, 28, 29, 30, 33
	Mistrust in health institutions	9	6, 11, 20, 22, 27, 31
	Healthy bodies	9	17, 22, 26, 33
	Social norms	6	2, 13, 14, 17, 27
	Vaccination not a priority	6	16, 18, 19, 21, 26, 32
	Against vaccination in general	6	18, 25, 27, 29, 31, 32
	Alternative prevention methods	5	12, 16, 24, 26, 27
	Diseases are beneficial	4	17, 22, 26, 27
	Fear of injection	4	13, 20, 27, 30
	Previous negative experiences	4	16, 17, 26, 32
	Humans too weak to fight vaccines	3	11, 17, 27
	Responsibility if something bad happens	2	11
Vaccine and vac- cination issue influences	No medical need	9	13, 15, 16, 19, 23, 25, 27, 29, 32
	Access	7	2, 14, 16, 18, 19, 24, 31
	Financial cost	6	2, 20, 24, 30, 32, 33
	Lack of recommendation from providers	4	18, 29, 31
	Vaccine novelty	2	24, 27
	Inconsistent advice from providers	2	6, 24

<sup>\*</sup>Determinants can be recorded more than once in an article (e.g. different types of conspiracy theories mentioned).



# Advice and guidance for public health programme managers on addressing vaccine hesitancy and strengthening confidence in vaccination

Advice and guidance is presented here on general actions that can be taken within the public health and healthcare systems to enhance vaccine confidence and overcome obstacles to vaccine uptake. Guidance is also presented on ways in which programme managers can support healthcare providers in their work with hesitant populations.

Studies show mixed evidence on the effectiveness of interventions targeting vaccine hesitancy. This is partly due to the specificity of such interventions in different circumstances, cultures or countries and in relation to different vaccines. An intervention to improve influenza vaccination, for example, might be successful in a particular country, population, or even timeframe (e.g. an outbreak of pandemic influenza) but unsuccessful in another. Nonetheless, a variety of strategic considerations were found in the literature to be generally applicable.

## **Improving communication and information**

# Listen: gain insights into the determinants of vaccination hesitancy in your context

Hesitancy encompasses a wide variety of contextual, individual, group, vaccineand vaccination-related determinants. Interventions need to be specific and adapted to the identified determinants of vaccine hesitancy in various populations. Interventions may be needed on an individual level (dialogue, better information), or on a logistic or system level.

Conducting formative research with focus groups or interviews with representative members of hesitant populations is one activity that programme managers can undertake to gather insights into perceptions, attitudes, knowledge and behaviour. Monitoring social media and websites of groups and communities that represent vaccine hesitant and sceptical views is also useful. This latter approach enables ongoing monitoring and early identification of potential changes in beliefs and the development of new determinants of vaccination refusals. Active monitoring of the media, particularly of the comments and discussions on websites (see, for example, the Vaccine Confidence Project<sup>i</sup>), blogs and forums, although time consuming, can help identify rumours and misinformation early, allowing for a quick response.

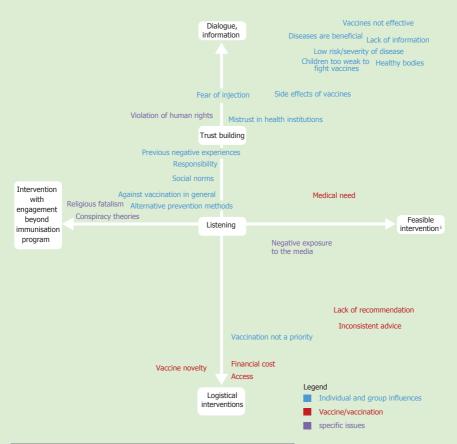
### Match interventions to determinants of hesitancy

Specific determinants of vaccine hesitancy need to be addressed using methods and types of interventions relevant to the issue and the context. The LSHTM Vaccine Confidence Project has developed a matrix to help inform the design of interventions based on these determinants (see Figure 2). Certain determinants such as individual beliefs in risks of vaccination and low risk of getting the disease, for example, can be addressed through discussions, information, and educational interventions. Others, such as mistrust in institutions, require broader interventions that will build trust in health systems and vaccines (e.g. development and enforcement of regulatory initiatives on vaccine safety and adverse event reporting systems). Certain determinants simply require logistical interventions such as reducing costs or improving access by extending opening times or identifying more convenient immunisation sites.

http://www.vaccineconfidence.org

The biggest challenge lies in hesitant populations with determinants and beliefs which are difficult to control or alter. These include religious beliefs or people believing in conspiracy theories. Although there are ways to work with these populations (for instance, by collaborating with religious or community leaders) these determinants are based on strongly rooted ideologies which constitutes one of the most difficult type of behaviour change. These types of behaviour might not be addressable by short-term, general interventions.

Figure 2
Matrix of vaccine hesitancy determinants and interventions



<sup>&</sup>lt;sup>i</sup> In this context, this refers to easy to implement, upfront interventions.



#### Contextualise design, format and content

Tailor content to the identified information needs of target populations. Involve hesitant populations in planning and designing the interventions. Select messengers, settings and channels as determined by the specific needs of population groups and requirements of the country or region where the intervention takes place. For instance, in countries where young people have very little contact with healthcare providers, human papillomavirus (HPV) vaccination training and educational campaigns can usefully take place within youth centres or schools.

Tailor content to issues related to specific vaccines. Unlike other pharmaceutical products, all vaccines tend to be conceptually bundled into a single category. Perceptions of safety, efficacy and confidence in each different vaccine shapes overall determinants of hesitancy. Unbundling debates and discussions to focus on specific vaccines can allow for differential uptake and flexibility.

Ensuring a continuous provision of information to the public, with regular updates and monitoring, is likely to be beneficial. Reliable and trustworthy information sources should be available 24/7 for everyone. Clear and effective messages need to be easy to find. Interventions can include mass communication campaigns, which consist of the distribution of comprehensive information to the entire population and personalised communication campaigns which target specific hesitant populations and their needs or requirements, for instance through consultations with a healthcare provider.

Table 2
Summary of recommendations for content of communication strategies and interventions

	Recommendations	Reference
Design	Tailor content by conducting health needs assessments and by making use of existing social networks	6, 13, 18
	Involve hesitant populations in design	20, 33
	For online communication campaigns: use search engine optimisation to improve visibility	12
Format	Specific and adapted to determinants identified for targeted audience	18, 34
	Clear, effective, and easy to find	20, 33
	Continuous information, with regular updates and monitoring	24
	For online communication campaigns, transparent and monitoring hesitant populations	12
Content	The risk and consequences of diseases	17, 24, 27, 29, 33
	The risk of not being vaccinated	17, 24, 27, 29, 33
	Effects of vaccines on the immune system	17, 24, 27, 29, 33
	Alternative modes of prevention and how they compare to vaccination	17, 24, 27, 29, 33
	For online communication campaigns, avoid criticising hesitant populations, empower individuals to ask doctors the right questions, clear and easy-to-understand facts on vaccination, ability and responsibility to protect others (children)	12

## **Supporting healthcare providers**

This guide should be used in conjunction with ECDC's communication guide *Let's talk about protection* [1]. It provides a wide range of advice and guidance for healthcare providers on ways to improve their vaccination conversations and support people's 'vaccination journeys'. While it is not specifically focussed on hesitancy, much of the advice and guidance is relevant and can be used to help interactions with hesitant populations. Moreover, it has been adapted into a variety

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.

of European contexts and languages (e.g. in Bulgaria, Croatia, the Czech Republic, Estonia, Greece, Hungary and Romania). ECDC has used the lessons learned from these national adaptation experiences to develop a guide on a stakeholder-based approach to adaptation [5].

#### Address vaccine hesitancy among healthcare providers

Multiple studies show that in all European Union countries, healthcare providers are identified as the most important and trusted source of information on how to be protected from vaccine-preventable diseases [6-8]. This is particularly true for parents with the most questions and concerns. The personal credibility of the provider and their trust-based relationships with patients place them in unique positions to help support parents in understanding vaccination and choosing to get their children protected and in turn to protect others by being vaccinated.

The ECDC-commissioned qualitative study on hesitancy, however, shows that there are healthcare providers who themselves are hesitant and have concerns about vaccination [4]. The interviews conducted in Croatia, France, Greece and Romania revealed that although the providers interviewed were aware of the benefits of vaccination, most of them also had some concerns about the risks of vaccinating i. In the qualitative study they discussed the balance between risks and benefits of vaccination, their responsibility as doctors to prevent disease, the low risk of side effects, the importance of herd immunity and the prevention of serious illness and large disease outbreaks. However, they also discussed their concerns about vaccination, with providers in each country reporting different concerns: For example, Greek providers mostly discussed the number of vaccines children receive, which they perceived as too high, especially for young children. They also discussed the low efficacy of vaccines, especially influenza and their patients' concerns about side effects. Vaccine safety was the most important theme in Romania, where providers themselves had doubts about the risks of vaccination and expressed strong feelings of guilt and responsibility for side effects.

Efforts to address determinants of hesitancy in the general population are doomed to fail if healthcare providers are not on board. Public health agencies should consider the development and implementation of information and training programmes to address their expressed needs and concerns. (see Box 1 and Figure 3).

It should be noted that the views of the healthcare workers interviewed in this study may not be representative of the views of the general population of healthcare workers and must therefore be interpreted with caution.

# Box 1 Selected key 'concern' statements by healthcare providers as reported in ECDC-commissioned study [4]

There are too many vaccines

Children are too young to be vaccinated

Trust is an important influencer on vaccination and we have mistrust especially of the pharmaceutical industry (and of the health authorities in some countries)

We are not comfortable talking to patients about concerns around vaccination

Side effects and safety (especially adjuvants) – it is the doctor's fault

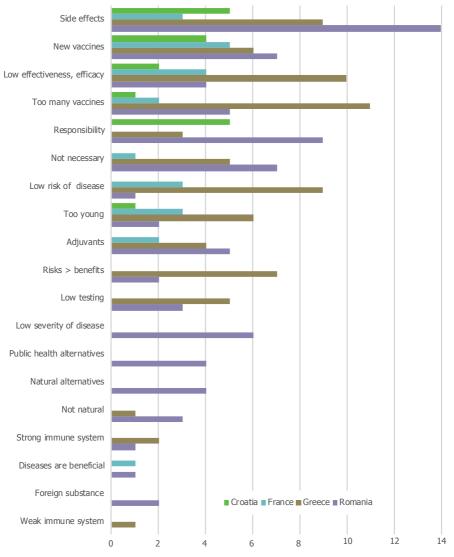
There are natural alternatives to vaccines

Diseases are beneficial for the immune system

Vaccines are not needed anymore because these diseases no longer exist or there is a very low chance of getting them



Figure 3
Snapshot of type of concerns expressed about vaccination and vaccine-preventable diseases by healthcare providers in four countries



Number of mentions of a theme during the qualitative study

Source: European Centre for Disease Prevention and Control. Vaccine hesitancy among healthcare workers and their patients in Europe – A qualitative study. Stockholm: ECDC; 2015. This snapshot above shows some recurrent concerns that were mentioned across the countries where the qualitative study was done, as well as some themes that were mentioned more often in specific countries. The ECDC guide *Let's Talk about Protection* provides general and specific advice (with sample questions and answers) regarding such concerns [1].

# Be transparent: ensure that information on vaccination policy, licensing and quality control is publicly available

In addition to vaccine and vaccination concerns, healthcare providers in the qualitative study expressed concerns about the reliability of vaccine safety information, the influence of the pharmaceutical industry on policy decisions, the quality of national licensing procedures and liability issues related to untoward outcome. These concerns need to be addressed with regular open dialogue between healthcare providers and the health and regulatory authorities. As concerns vary, programme managers should gather information relevant to their own contexts and address the needs expressed.

# Support healthcare providers with communication training and tools specifically related to hesitancy

The ECDC-commissioned literature review and healthcare providers that participated in the qualitative study identify the need for enhancing skilled communication between providers and patients and to improve training for providers [4]. Communication advice includes the following points.

**Frame interventions around empowerment.** Experts advise against criticising hesitant populations but rather empowering them to ask questions of their healthcare provider and provide them with clear and easy-to-understand facts. They also stress the importance of highlighting people's ability to protect themselves and their children in their environment and region, and of underlining that they have the right but also the responsibility (e.g. to contribute to herd immunity) of choosing to vaccinate themselves and their children. 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. <sup>ii</sup>

It should be noted that the views of the healthcare workers interviewed in this study may not be representative of the views of the general population of healthcare workers and must therefore be interpreted with caution.

ii See Let's talk about Protection Sections 1 and 2 for additional advice [1].

**Acknowledge errors and side-effects.** Interventions which solely promoted favourable attitudes to vaccination were not found to improve attitudes. Potential side-effects and risks of vaccination need to be acknowledged but put in perspective. To help build and maintain trust, provide information in a transparent manner, acknowledge past errors and vaccine side-effects, but give examples of current successful cases, such as the elimination of certain diseases.

**Demonstrate commitment to vaccination.** Evidence confirms that communication from providers of vaccination were more successful when they were presumptive (assuming that patients will get vaccinated) rather than participatory (asking patients how they feel about vaccination).

**Develop screening tools.** Use of pre-screening tools (see Boxes 2 and 3) at vaccination centres can help inform healthcare providers of the possible hesitancy of parents. Intelligence gathered from such screening can allow healthcare workers to tailor and adapt their messages and communication strategies to address specific claims and inform patients on areas of concern and misperceptions.

# Box 2 Example of a pre-screening tool

The Parent Attitudes About Childhood Vaccines (PACV) Survey was designed by Opel, et al [9] to measure vaccine hesitancy among parents in the general population. It includes three major categories of questions: immunisation behaviour, safety and efficacy, and general attitudes and trust. Parents' responses to these questions allow the calculation of the 'PACV score' by assigning 2 points for every 'hesitant' response, 1 point for 'don't know' or 'not sure' answers and no points for 'non-hesitant' responses. Points are then summed up and converted to a scale from 0 to 100 to provide the PACV score. A study was conducted to determine the predictive validity and test-retest reliability of the PACV. Researchers found that increases in parental PACV scores to at least 50 obtained at a child age of 2 months predicted a significant and incremental increase in underimmunisation at 19 months of age [10]

# Box 3 Examples of screening questionnaire

#### Immunisation behaviour

- Have you ever delayed having your child get a shot for reasons other than illness or allergy?
- Have you ever decided not to have your child get a shot for reasons other than illness or allergy?
- How sure are you that following the recommended shot schedule is a good idea for your child?
- It is my role as a parent to question shots.
- If you had another infant today, would you want him/her to get all the recommended shots?
- Overall, how hesitant about childhood shots would you consider yourself to be?

#### Beliefs about vaccine safety and efficacy

- Children get more shots than are good for them.
- I believe that many of the illnesses shots prevent are severe.
- It is better for my child to develop immunity by getting sick than to get a shot.
- It is better for children to get fewer vaccines at the same time.
- How concerned are you that your child might have a serious side-effect from a shot?
- How concerned are you that any one of the childhood shots might not be safe?
- How concerned are you that a shot might not prevent the disease?
- Do you know of anyone who has had a bad reaction to a shot?

#### **General attitudes and trust**

- The only reason I have my child get shots is so they can enter day-care or school.
- I trust the information I receive about shots.
- I am able to openly discuss my concerns about shots with my child's doctor.
- All things considered, how much do you trust your child's doctor?

Source: adapted from Opel DJ, Mangione-Smith R, Taylor JA, Korfiatis C, Wiese C, Catz S, et al.

Development of a survey to identify vaccine-hesitant parents: The parent attitudes about

Childhood Vaccines Survey. 2011. Human Vaccines 7(4), 419-425



**Provide positive messages.** Healthcare providers in the ECDC-commissioned study identified a wide variety of 'positive' messages that they used to make the case for vaccination. For example:

# Box 4 Selected positive messages used by healthcare providers as reported in ECDC-commissioned study [4]

Vaccines
not only protect
yourself and your
child but also other
vulnerable individuals,
e.g. people suffering
from cancer or
immune diseases

Vaccines are one of the most important scientific discoveries that help protect against serious, sometimes deadly diseases

Vaccination benefits outweigh their risks

## **Concluding remarks**

## Making a 'country-specific' case for vaccination

While most current interventions focus on education and improving information about vaccine safety, vaccine effectiveness, or the need for vaccines, concerns raised in the ECDC-commissioned study and elsewhere identify other determinants of hesitancy that need to be addressed. These include trust in healthcare systems, and providers' perceived roles in responding to patient hesitancy and their levels of confidence in doing so. Although some commonalities between countries can be found, such as the presence of vaccine-hesitant healthcare providers and concerns about vaccine safety and utility, determinants of hesitancy have also been shown to be country- and context-specific and need to be addressed as such.

National vaccination programmes have to be strengthened to develop the capacity to identify local determinants of vaccine hesitancy, whether in patients or in healthcare workers. They need to develop strategies which are adapted to address these determinants, in their own social, cultural, political and economic context.



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