

# **Vaccination and Patients with Chronic Conditions**

## **Background Report**

Commissioned by the European Patients' Forum

2018

## Contents

About this report .....	3
What is vaccination?.....	4
The importance of vaccination for patients with chronic conditions .....	5
<i>Diabetes and Seasonal Influenza Vaccination – Dominic’s story</i> .....	6
Information needs of patient communities .....	7
Gaps in information .....	10
<i>The role of the patient community – Peter’s story</i> .....	12
Vaccine hesitancy and its relevance to patients with chronic conditions .....	15
<i>Vaccination is a question of solidarity – Frank’s story</i> .....	18
<i>Addressing vaccine hesitancy in patient communities</i> .....	18
Vaccines policies and regulatory frameworks.....	20
<i>Vaccination plans</i> .....	21
Recommendations.....	23
References, sources of information and further reading.....	25

## About this report

In 2018 the European Patients' Forum commissioned this background report as part of its initiative addressing vaccination communities of patients of chronic conditions. The objective of the EPF initiative is to:

- contribute to increasing vaccine take-up, including transforming vaccine hesitancy to confidence in groups of patients with chronic diseases for whom specific vaccination recommendations exist in national immunisation programmes, but in which adherence to these recommendations is low due to various reasons including lack of awareness and information;
- raise awareness of the benefits of vaccination in these difficult-to-reach groups of patients, in collaboration with the EPF EU-wide membership.

EPF focused on the following elements:

1. Identifying key information gaps and information needs of the patient community with regards to vaccination;
2. Mapping any controversial issues for patients as well as challenges encountered by patient organisations (and national/international authorities) when addressing these issues.
3. Identifying existing tools, good practices and recommendations regarding information on vaccination suitable for the patient community, on which we can build EPF's recommendations.

EPF was supported in the initiative by Catherine Hartmann, a consultant in health policy, who drafted the background report on which the present summary report is based. The final draft was reviewed by an independent scientific expert. The aim of this report is to help EPF support its members – patient organisations active in specific chronic conditions at EU-level and national patients' coalitions in different EU Member States – in addressing insufficient uptake of vaccination with appropriate patient-centred information and advocacy tools.

This report outlines key concepts about vaccination and reviews the reasons why some patients living with a chronic condition may not take up vaccinations to protect themselves from the main vaccine-preventable diseases that could worsen their condition, including but not limited to vaccine hesitancy.

### **Limitations**

The report is based on desk research as well as information collected from patients, patient associations and other sources. A key limitation we found is the lack of data and information on vaccine uptake and/or hesitancy by patients with chronic diseases. It appears that there is very little published research in this field at European and international level. We found no systematic monitoring or registering of adults living with a chronic disease who are/are not vaccinated according to the specific recommendations, e.g., against the main infectious diseases. The reasons for the absence of vaccination in patients are also not the subject of any major studies that we could find. The conclusions we present in this report are therefore tentative and based on conclusions drawn from the EPF survey, interviews conducted with patients, and a general analysis of factors in lack of vaccination uptake (including hesitancy) and information needs, extrapolating these to the specific case of chronic disease patients. The EPF survey suggests certain issues in the patient communities that will warrant further investigation to understand better the specific concerns which may be different depending on the country and disease-area. It should also be noted that any tools developed on this basis will again undergo testing and validation with patient organisations, to ensure they satisfy their specific needs of patient advocates.

## What is vaccination?

In this first part, we define the key concepts developed throughout this report and put them in their context to better understand the main influencers in the choice to be vaccinated or not, as well as the main reasons for insufficient uptake of vaccination within at-risk groups.

### Definitions

**Vaccination**<sup>1</sup> is the use of vaccines to protect from infectious illnesses. **Immunisation** is the process of becoming immune to (i.e., protected against) a disease. Immunity can be provoked by vaccines or by having been previously sick from the disease; for instance, a person may become immune against chickenpox after having the infection, or thanks to the vaccine which prevented the disease. Vaccination helps both prevent and fight a disease – see below.

Vaccination also protects unvaccinated people through **community immunity**, also known as **herd protection**: when a large enough majority of people are vaccinated and therefore immune, they do not transmit the disease. Community immunity therefore indirectly protects those people who are not vaccinated (for whatever reason) and reduces the number of persons likely to contribute to the spread of a disease.

“[T]he question of vaccination is one of public health and of solidarity ... the healthy population should help protect those living with a chronic condition.”

Frank, 65, rare disease

**Vaccines** are medicinal products that produce immunity, therefore protecting the body from disease. Vaccines contain dead or weakened forms of the disease-causing micro-organism (pathogen). Vaccination triggers a person’s immune system to respond with the production of **antibodies**<sup>2</sup>— substances that weaken or destroy disease-causing organisms. Vaccination enables the development of “memory” in the immune system, so it is able to recognise the pathogenic agent again if it were to come in contact with the person later.<sup>3</sup>

### Types of vaccines

There are vaccines to prevent infectious diseases caused by bacteria and viruses. Vaccines are also increasingly being developed to treat certain conditions, but those are not covered in this report.<sup>4</sup> Preventive vaccines fall under four main types: *Live-attenuated vaccines* use a weakened (“attenuated”) form of the pathogen that causes a disease; *inactivated vaccines* use the killed version of the germ that causes a disease; *subunit, recombinant, polysaccharide and conjugate vaccines* use specific pieces of the germ; *toxoid vaccines* use a toxin (harmful product) made by the pathogen that causes a disease, inactivating or suppressing the toxin.<sup>5</sup> Information on vaccines that exist for different diseases or are being developed if available from the World Health Organization.<sup>6</sup>

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<sup>1</sup> From Latin *vacca*, cow. The first inoculations were given with organisms that caused the mild disease cowpox to produce immunity against smallpox.

<sup>2</sup> Antibodies are proteins in the blood that the body produces in response to foreign substances, such as bacteria or viruses, invading the body. Antibodies protect the body from disease by binding to these substances and destroying them.

<sup>3</sup> Source: INSERM <https://www.inserm.fr/en/health-information/health-and-research-from-z/vaccines-and-vaccination>

<sup>4</sup> On therapeutic vaccines, see for example <https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/immunotherapy/types/vaccines-to-treat-cancer>

<sup>5</sup> Source : <https://www.vaccines.gov/basics/types/index.html>

<sup>6</sup> <http://www.who.int/immunization/diseases/en/>

## The importance of vaccination for patients with chronic conditions

More and more diseases may be prevented and/or treated through vaccination. Adults are recommended to receive vaccinations based on their age, underlying medical conditions, lifestyle, prior vaccinations, and other considerations. It is particularly important for patients with chronic diseases to be vaccinated because their immune system is weaker and they are more likely to develop complications of the condition which may involve long-term illness, hospitalisation, and even death, from certain vaccine-preventable diseases.

Below we list generally recommended vaccines for some chronic conditions, based on information available from the US Centres for Disease Control and Prevention.<sup>7</sup> It should be borne in mind, however, that each country has different recommendations, and although there are similarities the ages and included conditions are not the same everywhere.

1. **Influenza (flu) vaccine** every year to protect against seasonal flu, in particular for people who have:
  - i. Asthma;
  - ii. Neurological and developmental conditions, including disorders of the brain, spinal cord, peripheral nerves and muscles, such as cerebral palsy, epilepsy or other seizure disorders, stroke, intellectual disability, moderate to severe developmental delay, muscular dystrophy, or spinal cord injury;
  - iii. Chronic lung disease, such as asthma, chronic obstructive pulmonary disease (COPD) or cystic fibrosis;
  - iv. Heart disease, such as congenital heart disease, congestive heart failure or coronary artery disease;
  - v. Endocrine disorders, such as diabetes mellitus type 1 or 2;
  - vi. Blood disorders, such as sickle cell disease or thalassaemia;
  - vii. Kidney, liver or metabolic disorders, such as inherited metabolic disorders or mitochondrial disorders;
  - viii. Weakened immune system due to disease or medication, such as people living with HIV or AIDS, cancer, or treated with chronic steroids;
  - ix. People younger than 19 years who are receiving long-term aspirin therapy;
  - x. People with obesity, having a body mass index (BMI) of 40 or more; people over 65.
2. **Td vaccine** every 10 years to protect against tetanus and diphtheria;
3. **Tdap vaccine** once, instead of Td vaccine, to protect against tetanus and diphtheria plus whooping cough (pertussis) and during each pregnancy for women;
4. **Pneumococcal vaccine**, is a routine vaccine for all children in most countries around the globe; in many countries, it is also recommended for adults of the age of 60 or 65 (depending on which vaccine) and/or for people with chronic heart, liver, kidney, or lung disease, diabetes, or alcoholism, and for people with conditions that weaken the immune system;
5. **A hepatitis B vaccine series**, in particular for people who have haemodialysis and/or dialysis treatment or have end-stage kidney (renal) disease, HIV infection, or chronic liver disease, or have diabetes and are under the age of 60;

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<sup>7</sup> For more information, see <https://www.cdc.gov/vaccines/spec-grps.html#conditions>

Other vaccinations may be needed, depending on factors such as country/area of residence, age, lifestyle, job, health condition, and the vaccines one has had in the past. Those may include shingles, human papillomavirus (which can cause certain cancers), pneumococcal disease, meningococcal disease, hepatitis A and hepatitis B, chickenpox (varicella), measles, mumps, and rubella.

Although there is no reliable data on vaccination coverage among patients with chronic conditions, the trend in some areas of Europe towards lower vaccination uptake has been concerning. According to the latest report from the European Centre for Disease Prevention and Control (ECDC), in 2017, the EU/EEA experienced a resurgence of measles, with several outbreaks and 37 deaths. The EU/EEA countries reported 14,600 measles cases, more than three times the number reported in 2016. The majority of cases were in unvaccinated persons. Within the broader European region, the number of measles cases quadrupled from 2016 to 2017.<sup>8</sup>

Measles can cause severe complications in adults, but infants (children aged under 1 year) are most at risk as “they cannot be vaccinated and have a six-fold risk of death according to analysis of ECDC data from 2013-2017 of this age group. Infants can only be protected through so-called ‘herd immunity’, which is when 95% of the population in a country are vaccinated with two doses of measles vaccine.”<sup>9</sup>

### **The case of seasonal influenza vaccination**

Seasonal influenza vaccination is highly recommended for people over the age of 65 and persons with chronic diseases, in all EU countries.

The EU target for influenza vaccination for adults living with a chronic disease is 75%. Yet, none of the EU countries report this level of coverage. Only 9 countries out of 28 reported their vaccination rates in this group to the ECDC. In those countries, coverage ranged from 24.9% to 71.8% (in 2014–15) with the median uptake rate for the same season being 50.3%.<sup>10</sup> The highest coverage rates for people with chronic conditions were reported by the United Kingdom and Northern Ireland. Comparisons are difficult because Member States use different methods to estimate their vaccination coverage, and as a consequence, there is no reliable data available in the EU on influenza vaccination coverage for patients with chronic conditions.

**“Healthcare professionals should explain to patients the high risks of not being vaccinated when the immune system is already affected by having a chronic condition.”**

*Dominic, 35, DMT<sub>2</sub>, Belgium*

There may be a general perception, shared also by some patients, that diseases being prevented by vaccination are “not so dangerous” and will not cause major harm. The following patient story, based on an interview, illustrates how patients can underestimate the severity – in this case of influenza – and thus not realise that missing their vaccination can result in a serious risk to their health and even life.

### **Diabetes and Seasonal Influenza Vaccination – Dominic’s story**

*Dominic, from Belgium, was diagnosed with Diabetes Type 2 when he was 35 years old. He always practised a high level of sports (rugby and skiing, in particular) and was living a healthy life, so the news of his disease took him by surprise but he learnt to adapt his diet to still be able to practise his favourite sports. Dominic fully understands immune system deficiency as he is a physician himself, and vaccination has always been something he undertook for himself, without questioning it and following medical*

<sup>8</sup> [https://ecdc.europa.eu/sites/portal/files/documents/Measles-and-Rubella-Surveillance-2017-final\\_0.pdf](https://ecdc.europa.eu/sites/portal/files/documents/Measles-and-Rubella-Surveillance-2017-final_0.pdf)

<sup>9</sup> <https://ecdc.europa.eu/en/news-events/measles-vaccination-gaps-teenagers-and-young-adults-highlighted-ecdc-report>

<sup>10</sup> Source: ECDC <https://ecdc.europa.eu/sites/portal/files/documents/influenza-vaccination-2007%E2%80%932008-to-2014%E2%80%932015.pdf>. The nine countries were the UK, Netherlands, Norway, Belgium, Germany, France, Portugal, Ireland and the Czech Republic.

guidelines. Because of the nature of his work, vaccination against hepatitis is mandatory. His employer also provides free influenza vaccine every year at the hospital.

Last year he missed the date and his appointment, but he did not worry too much as he felt strong and equipped to face a potential risk of catching the disease. Sadly, this assumption was wrong.

When Dominic did fall ill with influenza in March, the disease almost killed him. He had extremely high fever and delirium, which led him to refuse to be taken to hospital. He ended up in a near-coma state. His family, taking care of him, did not know quite how to feed him correctly to help the recovery, given his diabetes, which made things more complicated.

Dominic realises his luck of still being alive and hates his negligence with his flu vaccination appointment. He thinks that endocrinologists, at least in Belgium, have not yet integrated the necessity of vaccination in their treatment recommendations. The subject is rarely raised by diabetes specialists, who neglect sharing essential information on the matter with their patients – unlike pulmonologists, who Dominic believes do have a systematic approach to vaccination.

He would therefore recommend that specialists get further training and information in the importance of vaccination for people living with a chronic disease, in particular diabetes, and integrate it as part of the care pathway. He underlined the key role of healthcare professionals in explaining the high risks of not being vaccinated when one's immune system is already affected by a chronic condition.

## Information needs of patient communities

This section reviews the information needs as expressed by the EPF membership, drawing also on relevant literature.

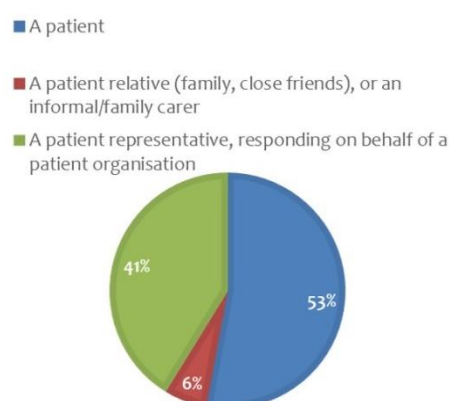
In a survey conducted in March and April 2018, the European Patients' Forum asked its members questions in relation to vaccination. The survey received 34 responses, split between individuals and organisations, from 12 EU countries: Andorra, Austria, Croatia, Cyprus, France, Greece, Hungary, Japan, Poland, Portugal, Romania and Spain. Several disease-areas were represented.

In its survey of March/April 2018, EPF asked members if vaccination was an important priority for patients with their conditions, and if there were specific problems related to vaccination as a result of having the condition; if vaccination was an important issue in their country; and if vaccination hesitancy was an issue in the specific disease patient community or country.

The majority of respondents answered yes to all questions, underlining the importance of vaccination hesitancy and of responses to be provided to it. When asked if they had found good sources of information on vaccination (for example, campaigns, or websites), EPF members answered No in majority.

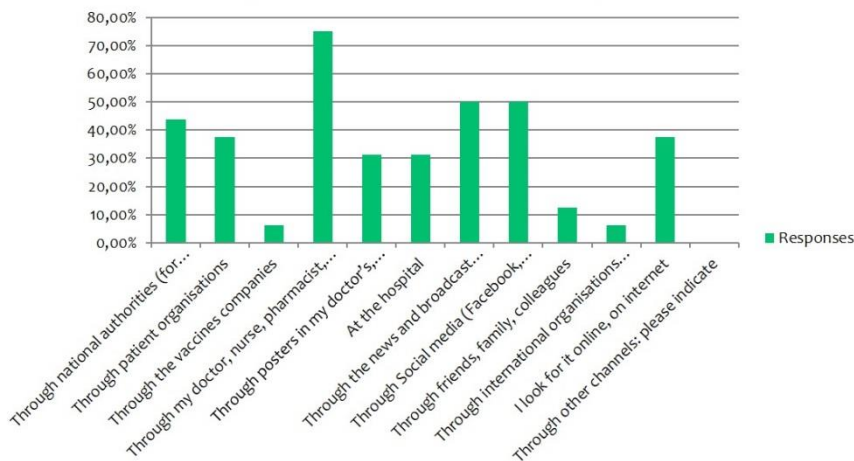
It seems that patients with chronic diseases may not find specific information related to their condition easily, or from their regular sources of information.

The research did not result in finding adequate information on vaccination for people living with a cardio-vascular disease, diabetes or cancer for instance. Only the Centers for Disease Control and Prevention (CDC),<sup>11</sup> in the USA, offers comprehensive webpages on vaccination recommendations per chronic diseases.



<sup>11</sup> Source : CDC <https://www.cdc.gov/features/vaccineschronicconditions/index.html>

### Where do you get information on vaccination in your disease-area / country?



Patients who answered the EPF survey may have been proactively looking for information because of their ill-health, being already more knowledgeable about health risks due to their existing condition.

Their carers who are mainly specialist doctors will also have followed a protocol which includes treatments with vaccines.

However, when pro-actively searching for information themselves and via other sources, they found very little.

### Sources of information

**Healthcare professionals.** Professionals, including nurses, medical doctors, dentists and pharmacists, are key providers of information on vaccination. For patients, they are the main messengers and conveyors of recommendations for immunisation. They are generally the most important and trusted source of advice for patients on questions pertaining to health. This is consistent with research:

- In a US study, parents who changed their attitude following an earlier decision to not have their child vaccinated, cited “information or assurances from healthcare providers” as the main reason for their change of mind.<sup>12</sup> However, following recent media stories and debates on the safety of the pandemic influenza vaccination, the perceived trustworthiness of healthcare professionals may have suffered.<sup>13</sup> Whereas vaccine confident persons will trust their healthcare professionals, vaccine hesitant persons will consult several sources of information.
- A 2012 French study showed that the vast majority of those who refused vaccination mentioned multiple information sources, such as the media, people close to them (family, friends, and colleagues), and healthcare providers. They usually consulted several healthcare professionals, including doctors and nurses in public institutions as well as doctors and other medical professionals in private practice.<sup>14,15</sup>

All studies reviewed for this paper stress that a person’s attitude towards vaccination relies mainly on information obtained from various sources, but also beliefs, perceptions and often rumours (positive or negative).

One of the main barriers could be insufficient information to patients from healthcare professionals, and/or lack of assertiveness by the professional (sometimes the information is there, but the professional does not bring it to the patient’s attention and therefore vaccinations are perceived as not needed).

<sup>12</sup> Source: <https://www.ncbi.nlm.nih.gov/pubmed/18829793>

<sup>13</sup> Source : ECDC

[https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/1008\\_TED\\_conducting\\_health\\_communicati\\_on\\_activities\\_on\\_MMR\\_vaccination.pdf](https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/1008_TED_conducting_health_communicati_on_activities_on_MMR_vaccination.pdf)

<sup>14</sup> <http://journals.plos.org/plosone/article/authors?id=10.1371/journal.pone.0034054>

<sup>15</sup> Source Eurosurveillance : <https://www.eurosurveillance.org/images/dynamic/EE/V16N17/art19849.pdf>



We identify potential issues around professionals’ training in this area, as well as the potential impact of vaccine hesitancy among professionals.

### Infographic available from [WHO](#):

**5 FACTS ON VACCINES**  
There's a lot of conflicting information out there about vaccines. Question what you read and hear – and understand the facts.

**1. Vaccines are safe and effective.**  
Any licensed vaccine is rigorously tested before it is approved for use, regularly reassessed and constantly monitored for side effects. In the rare event a serious side effect is reported, it is immediately investigated.

**2. Vaccines prevent deadly illnesses.**  
Vaccination protects children from diseases like diphtheria, measles, mumps and pertussis (whooping cough). Failure to vaccinate leaves children and adults vulnerable to diseases, complications or even death.

**3. Vaccines provide better immunity than natural infections.**  
The immune response to vaccines is similar to the one produced by natural infection, but less risky. For example: natural infection can lead to cognitive impairments from Haemophilus influenzae type b (Hib), birth defects from congenital rubella infection or irreversible paralysis from polio.

**4. Combined vaccines are safe and beneficial.**  
Giving several vaccines at the same time has no negative effect on a child's immune system, reduces discomfort for the child, and saves time and money. Children are exposed to more antigens from a common cold than they are from vaccines.

**5. If we stop vaccination, diseases will return.**  
Even with better hygiene, sanitation and access to safe water, infections still spread. When people are not vaccinated, infectious diseases that have become uncommon – diphtheria, measles, mumps and polio – quickly reappear.

World Health Organization  
Check with your doctor that you are fully vaccinated.

**Media, including the Internet.** In an article entitled “Innovations in communication: the Internet and the psychology of vaccination decisions”, the authors state that the reported *importance of the Internet* in health decisions is still low, but rising. In particular, interactive use of the Internet is increasing, e.g., due to the use of social media. The authors argue that the fact that individuals do not report the Internet as an important source of information does not necessarily mean that information obtained in their Internet searches is not influential in their decisions.

Internet searches can result in unreliable information being brought to the browser’s attention over reliable information. Websites on vaccination are found in abundance; but a quick search in English by the authors<sup>16</sup> found more anti-vaccination webpages or pro-“natural” treatments web pages than robust scientifically-based websites. A search with the simple word “vaccination” on YouTube resulted in 60% anti-vaccination videos. Interestingly, the search terms used are important: more specific terms result in fewer “anti-vaccine” sites, which suggests that a typical web surfer, coming to an issue for the first time and using broad search terms, is likely to be presented with the least accurate sample of web pages.<sup>17</sup>

Likewise, **the (non-Internet-based) media** are very important in relaying information on vaccination – consistently with the EPF survey – but unfortunately, highly improbable events, extraordinary claims implying a conspiracy, and steadfast beliefs with little support beyond anecdote often tend to be given more coverage than sound information based upon empirically valid and peer-reviewed research.<sup>18</sup> On the other-hand, studies from 2010 showed that mass media coverage of flu-related topics such as vaccine shortages and delays may boost overall vaccination rates and prompt people to get their shots earlier in the flu season.<sup>19</sup>

**Patient organisations** are the third main sources of information on vaccination for EPF survey respondents.

They “coordinate awareness campaigns that promote the effectiveness and safety of vaccines, and also work on the ground to dispel anti-vaccine myths through sharing both scientific facts and their

<sup>16</sup> Searched on 4 May 2018

<sup>17</sup> Source: Eurosurveillance <https://www.eurosurveillance.org/images/dynamic/EE/V16N17/art19849.pdf>

<sup>18</sup> Source : Psychology Today : <https://www.psychologytoday.com/us/blog/radical-behaviorist/201002/the-autism-vaccines-myth-the-impact-the-media>

<sup>19</sup> Source: <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1475-6773.2010.01127.x>

own experiences”<sup>20</sup>. According to a study on “Effect of narrative reports about vaccine adverse events and bias-awareness disclaimers on vaccine decisions: a simulation of an online patient social network”, patient networks can influence vaccination decisions by delivering risk-related information.<sup>21</sup>

**National and international authorities** National and international bodies also serve as trusted source of information, for healthcare professionals, the press, and researchers. Patients, informal carers and lay people may tend to proactively look for data and science provided in lay friendly language via other communication channels, such as patients organisations, but national authorities were identified as key information providers by respondents to the survey.

It is important that national health agencies, public research bodies, or governments publish accurate and evidence-based information as references and also actively reach out to the public, through information and awareness campaigns, and improve their communication expertise.

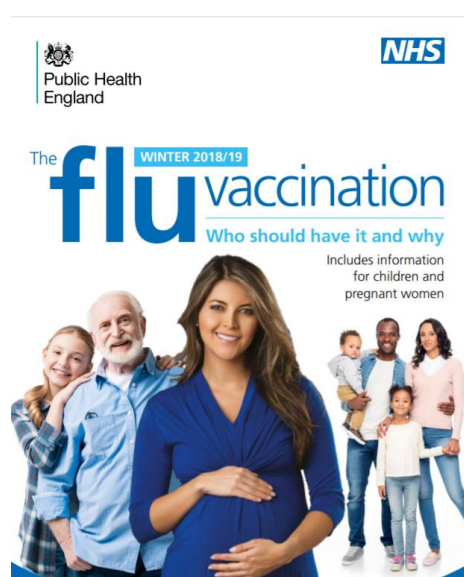
In a 2010 survey conducted after the H1N1 pandemic, it appears that National health authorities (such as Ministries, etc) and European authorities ranked as the second and third most trusted sources of information on the swine influenza; 61% of respondents would completely or mostly trust national authorities regarding such information and 52% would trust information received from European authorities<sup>22</sup>. The latter make available facts, figures and recommendations in the form of leaflets, brochures, videos, and technical documents that patient organisation or healthcare professionals may use and adapt for their own benefit. They are not influenced by commercial interests and are based on robust science.

## Gaps in information

The EPF survey respondents identified as key issues a lack of information on the benefits and potential risks of vaccinations, and added the following spontaneous concerns via open-ended questions:

- Lack of information that is *trusted*;
- Patients get divergent information from different sources, including from different healthcare professionals;
- Need for “one trusted, comprehensive and accessible source of information” ideally at EU level;
- Need for information on side effects for specific patients, including possible serious adverse events;
- Information on the safety of vaccines.

The majority of the respondents said that what is missing is information on vaccination in relation to specific chronic conditions, and information on the risks of *not* being vaccinated. Respondents also



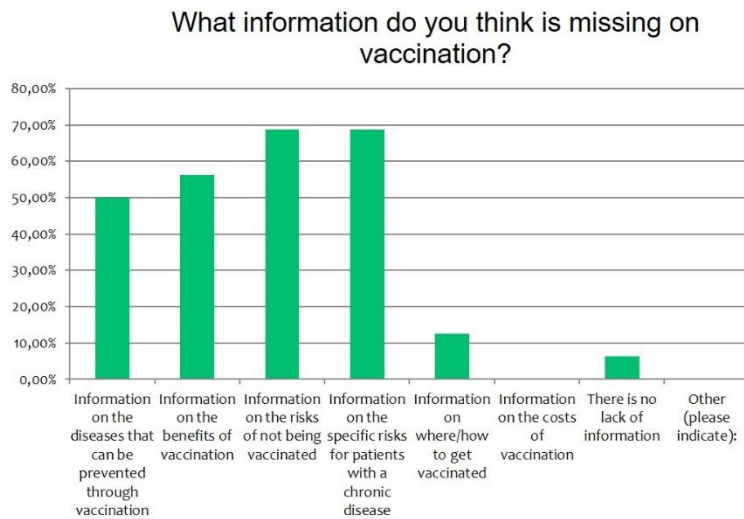
**Leaflet explaining the importance of the influenza (flu) vaccination**  
Source: [NHS, UK](#)

<sup>20</sup> Quote Sam Nye, executive director of the Confederation of Meningitis Organisations (CoMO), in EurActiv, 24 April 2018

<sup>21</sup> <https://www.ncbi.nlm.nih.gov/pubmed/22875721>

<sup>22</sup> Source: European Commission: [http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl\\_287\\_en.pdf](http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_287_en.pdf)

mentioned information on the diseases that can be prevented with vaccination, and on the benefits of vaccination.

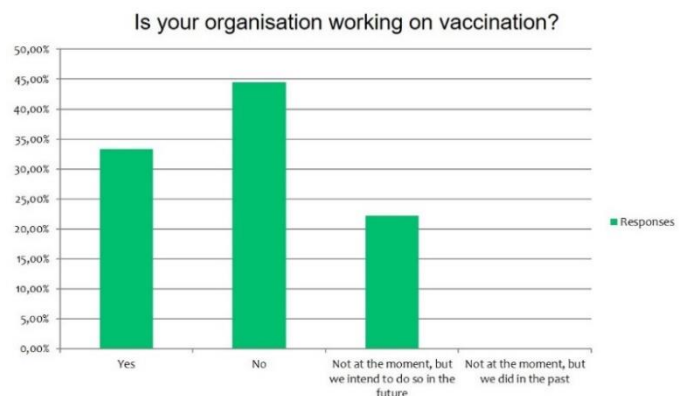


Some respondents think that the benefits of vaccination are well communicated but the risks are not, which may lead some patients to wonder whether the information available to them is fully transparent and comprehensive. It seems that careful, contextualised and accurate communication of risks in relation to benefits, in a lay-friendly, easily understandable language and format and from a trusted source, is needed.

Lack of, or poor information, together with “fake news” on vaccination can be harmful. Since the 2009 H1N1 (swine flu) pandemic experience, a decline in vaccination against seasonal flu was reported in 2014 for key target groups. All but two EU countries were falling short of the 75% coverage target set by the Council, leaving 60 million vulnerable adults unvaccinated every year.<sup>23</sup>

### **The role of patient organisations**

Some of the patient organisations responding to the EPF survey said they were active on the topic of vaccination; however, more said they were not. Moreover, some disease-specific organisations in disease areas where specific recommendations exist, seemed not to be aware or to recognise its importance. Some patient organisations indicated they have an interest or plan to get more active on this topic in the future.



Some disease-specific patient organisations participate in the promotion of vaccination. The European Federation of Allergies and Airways Disease Patients’ Associations (EFA) shares information about the importance of influenza vaccination for respiratory disease patients with, in particular, its support for the “EU Manifesto on Influenza Vaccination”<sup>24</sup> and by circulating the EPF video “What matters to patients about vaccination” (April 2018). In addition, patients with respiratory diseases, or parents, can find in-depth information on the website of the European Lung Foundation (ELF) in several languages.<sup>25</sup>

The European Cancer Patient Coalition (ECPC) communicates on cervical cancer prevention as a partner in the EU-funded IMMUNISA project and through its collaboration with the European Society

<sup>23</sup> European Commission (2014) Staff Working Document, SWD(2014) 8 final, “State of Play on the Implementation of the 2009 Council Recommendation on seasonal influenza vaccination”, available at [http://ec.europa.eu/health/vaccination/docs/seasonflu\\_staffwd2014\\_en.pdf](http://ec.europa.eu/health/vaccination/docs/seasonflu_staffwd2014_en.pdf)

<sup>24</sup> Source: EFA <http://eufightingflu.com/>

<sup>25</sup> Source: ELF <http://www.europeanlung.org/assets/files/en/publications/vaccinationandlungdisease.pdf>

(ESMO), which publishes a brochure on survivorship for its patients, including a chapter on immunisation.<sup>26</sup> ECPC also promotes vaccination with the European Cancer Code: “Ensure your children take part in vaccination programmes for: Hepatitis B (for new-borns) and Human papillomavirus (HPV) vaccines”. Prevention through vaccination to avoid cancer is a key concern, but we could not find information of immunisation for existing cancer patients.

Peter’s story, below, illustrates the importance of patient organisation advocacy to increase uptake of vaccination in specific disease communities.

### ***The role of the patient community – Peter’s story***

*Peter, from Germany, is the leader of an HIV/AIDS patients’ association, active at national and European level. He is a public health advocate, a campaigner as well as a true supporter of community action to care for people living in a poor condition. A good part of his work focuses on taking care of most deprived population (e.g. migrants and prisoners) and on treatment issues.*

*Peter is vaccinated against the flu (yearly jab), hepatitis B, hepatitis A and tetanus. He has a genuine knowledge of vaccines benefits and promotes them among risk groups. When asked about the importance of vaccination among the patients he knows and works with, he answered, “It depends {on} whom you talk to, there are some sceptics but the HIV/AIDS community is a strong community, organised as such, in which patients listen and learn from one another”.*

*Peter believes that scientific evidence and health professionals are the key factors to convince the vaccine hesitant people; information on benefits and risks (facts) should be widely shared. He trusts there is a high level of vaccination in the HIV/AIDS population, thanks, in part, to the strong sense of community in which patients speak and share among themselves, including on the importance of vaccination.*

### ***The role of healthcare professionals***

As expressed through the EPF survey and in scientific literature, the role of healthcare professionals in the question of vaccination is one of utmost importance, often he or she is the single reason of choosing to be vaccinated or not. We learned from the patients interviewed that the relationship one has with one’s doctor, whether or not they proactively share information, and whether the professional is a “doubter” can reinforce or undermine vaccination uptake by the patient. This is particularly important because patients are already vulnerable physically and psychologically due to their health state: trust and confidence in what the healthcare professional says are the basis of a patient’s confidence in their care, and in vaccination.

Healthcare professionals report more and more questions from patients while having less time to answer them – hence increasing the likelihood of patients seeking information from other sources. Physicians are the main and most influential source of vaccination information, but they report facing increasing difficulties in building trustful relationships with patients; studies show many physicians feel there is not enough support from governments and health authorities. Other professionals such as particularly nurses and pharmacists, and anyone involved in a multidisciplinary care team, have important roles to play also and their messaging towards patients should be clear and consistent.

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<sup>26</sup> Source: ECPC and ESMO <http://www.esmo.org/content/download/117593/2061518/file/ESMO-Patient-Guide-Survivorship.pdf>

The Vaccine Confidence project<sup>27</sup> demonstrated that some healthcare workers felt comfortable responding to patients and believed they had sufficient information or resources to do so while others did not. Some also felt that they lacked sufficient information to be able to talk about vaccination and sometimes even shared similar doubts to those of their patients in relation to vaccines.

**“Specialists [should] get further training and information on the importance of vaccination for people living with a chronic disease, in particular diabetes, and integrate it as part of the care pathway.”**

Dominic, 35, DMT2, Belgium

Vaccination coverage among professionals is not optimal. Almost all countries recommended influenza vaccination for health-care workers, but the majority reported influenza vaccine uptake as being as low as 40%.<sup>28</sup> The European Centre for Disease Control (ECDC) lists a variety of interventions<sup>29</sup> tested with healthcare professionals, in particular on communication methods, to increase uptake of vaccination and concluded that there is no “magic bullet,” or single intervention strategy that works in all instances.

### **The importance of health professionals – Guy’s story**

*Guy, from France, is a 53-year old man who was diagnosed with lymphoma in 2000 and again in 2005. He was treated with chemotherapy and radiotherapy, followed by an allograft in November 2005. It was only when the latter was planned that he was advised to get the flu and pneumococcal vaccines – not when his lymphoma was first declared and treated, five years earlier. Guy is very involved with patient groups in France and is a strong believer in vaccination. Several disease-specific patient groups in France have formed an alliance to focus on vaccination for immune-depressed people.*

*Guy highlights that patients with a chronic disease are more literate about the importance of vaccination than the public at large, but that there is still a great lack of information, due in big part to healthcare professionals not communicating sufficiently on the matter with their patients. He believes that general practitioners as well as specialists in hospitals should be protected at least against the flu, pneumonia and hepatitis B – or inform patients by wearing a mask or a badge that they are not vaccinated. “If healthcare professionals do not lead by example and be vaccinated to protect the population they care for, how can they be credible and convey a message of good care?”, he added.*

*His work focuses on raising awareness on vaccination in a very pragmatic manner: sending information on recommended and contraindicated vaccinations to both patients and healthcare professionals, including vaccination in therapeutic patient education programmes, reminding professionals of the care guidelines for treating chronic diseases which include vaccination, ensuring that the free vaccination vouchers which the French administration makes available to patients with a chronic disease are distributed and used, and informing patient groups about the necessity of vaccination through events and communications.*

*Guy believes that vaccination hesitancy is due to a lack of information, mis-information and insufficient training of physicians on the matter.*

*Guy’s key recommendation is to try and convince physicians of the importance of vaccination, as he has met too many hesitant doctors and asks the latter to communicate the fact that they are not vaccinated, should it be the case, (for example) against the flu and pneumococcal with their patients, in order to be fully transparent.”*

This responses to the EPF survey and interviews demonstrate that patients feel they do have a role to play in changing healthcare professionals’ attitudes towards vaccination and would like to work with them to better inform and share knowledge on vaccination for adults living with a chronic disease.

<sup>27</sup> <http://www.vaccineconfidence.org/research/vaccine-hesitancy/>

<sup>28</sup> “How close are countries of the WHO European Region to achieving the goal of vaccinating 75% of key risk groups against influenza? Results from national surveys on seasonal influenza vaccination programmes, 2008/2009 to 2014/2015”, <https://www.sciencedirect.com/science/article/pii/S0264410X17317620>

<sup>29</sup> Source : ECDC : <https://ecdc.europa.eu/en/publications-data/catalogue-interventions-addressing-vaccine-hesitancy>

Based on the issues expressed by its members, EPF asked them what sort of tools it could develop to answer their needs and concerns. The answers included:

- Comparison of all EU countries (and against other countries) of the recommendations and coverage of vaccination;
- Recommendations on trustworthy and authentic websites;
- Information on specific risks for chronic disease patients (of diseases that can be prevented through vaccination);
- Information on the risks of vaccination, set in context of benefits;
- Data on side effects, information on national institutions and bodies patients can contact for more information on vaccines;
- Information on costs and where/when to get vaccinated.

Respondents said the information on specific vaccines should be validated and based on scientific literature, including the composition of vaccines, the number of injections needed. This information should be easily accessible and understandable by all including people with lower health literacy. Overall, robust, accessible, un-biased information on vaccination in relation to chronic conditions is the top need expressed, as well of the number one issue for most patients – in a time of an overflow and discontinued stream of news and information, one may find it difficult to form one’s opinion, if there is no clear guidance from trusted partners, such as patient organisations.

# Vaccine hesitancy and its relevance to patients with chronic conditions

*A lie can travel half way around the world while the truth is putting on its shoes.*  
- Mark Twain (attributed)

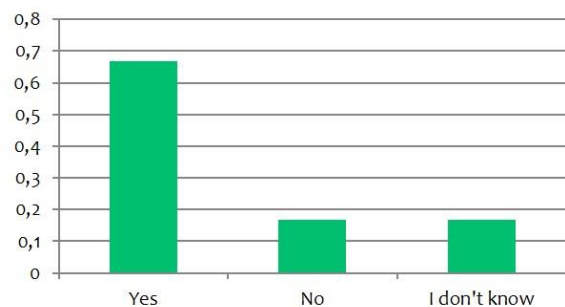
The second part of this report outlines issue with regard to vaccine hesitancy. The survey found hesitancy to be a factor in low uptake of vaccination by some patients, though it is by no means the only factor. However, given that most respondents said hesitancy is an issue either in their country or/and in their patient community, and the amount of literature there is on the subject, it is worth delving into in some detail. We believe that the information tools and recommendations developed by EPF can also be used, to some extent and depending on the context, to counter hesitancy by patients.

**Vaccine hesitancy** refers to “*delay in acceptance or refusal of vaccines despite availability of vaccination services. Vaccine hesitancy is complex and context specific, varying across time, place and vaccines. It is influenced by factors such as complacency, convenience and confidence.*” Hesitancy may influence a person’s decision to accept some or all vaccines in accordance with the recommended schedule.<sup>30,31</sup>

Vaccine-hesitant individuals are a heterogeneous group. Some people may refuse some vaccines, but agree to others, some may delay vaccines or accept vaccines while being unsure about doing so. Vaccine hesitancy exists across all socioeconomic strata of the population. Up to 20% of parents from five EU countries reported doubts about having their child vaccinated, in a survey by the WHO SAGE Group (data from 2008-2009).

Data on the prevalence and scope of hesitancy is not comprehensive, although some studies exist.<sup>32</sup> The reasons for hesitancy are well documented, though the rigour of the evidence could be improved, as most countries reported that their reasons were based on opinion rather than assessment.<sup>33</sup> The WHO SAGE group has developed the “3 Cs” model of vaccine hesitancy,<sup>34</sup> first proposed to the WHO EURO Vaccine Communications Working Group in 2011, which highlights three factors: complacency, convenience and confidence:

Is vaccine hesitancy an issue in your country?



<sup>30</sup> Source : WHO SAGE group:

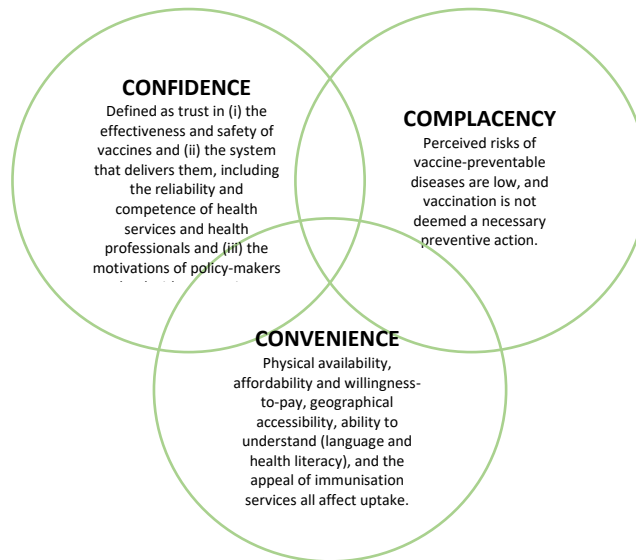
[www.who.int/immunisation/sage/meetings/2014/october/SAGE\\_working\\_group\\_revised\\_report\\_vaccine\\_hesitancy.pdf?ua=1](http://www.who.int/immunisation/sage/meetings/2014/october/SAGE_working_group_revised_report_vaccine_hesitancy.pdf?ua=1)

<sup>31</sup> [http://www.who.int/immunisation/sage/sage\\_wg\\_vaccine\\_hesitancy\\_apr12/en/](http://www.who.int/immunisation/sage/sage_wg_vaccine_hesitancy_apr12/en/)

<sup>32</sup> See for example WHO (2013) at [http://www.euro.who.int/\\_data/assets/pdf\\_file/0004/329647/Vaccines-and-trust.PDF?ua=1](http://www.euro.who.int/_data/assets/pdf_file/0004/329647/Vaccines-and-trust.PDF?ua=1)

<sup>33</sup> <https://www.sciencedirect.com/science/article/pii/S0264410X18304195#t0005>

<sup>34</sup> Vaccine hesitancy: Definition, scope and determinants/ <http://www.nitag-resource.org/uploads/media/default/0001/02/cef8f491c90d0f3b68a13421e16459b4fc15152b.pdf> Graph adapted from one presented in the article.

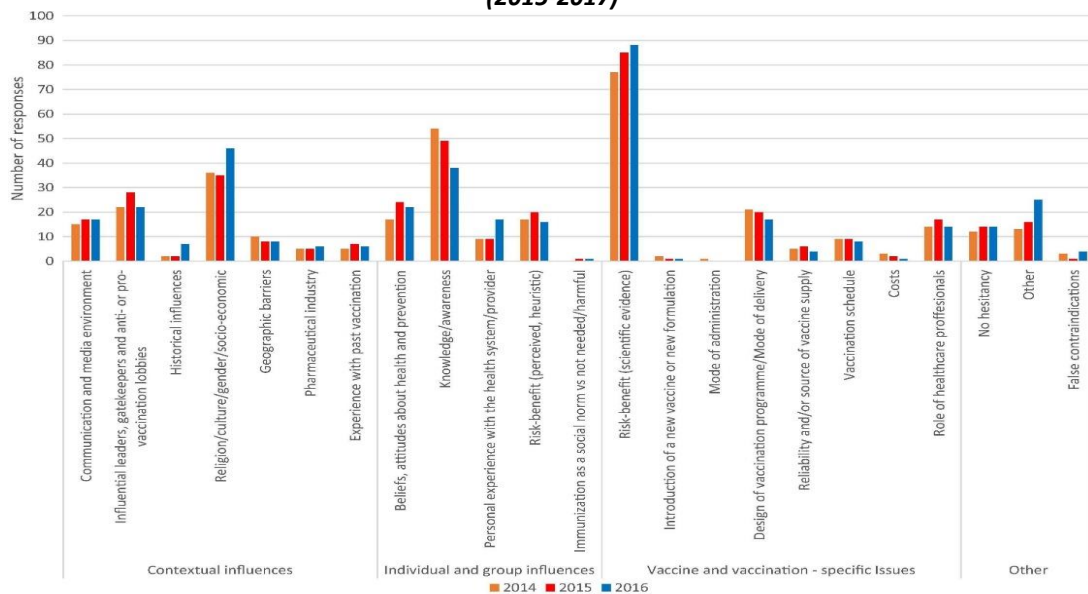


Another model is the **Spectrum of vaccine acceptance**, also developed by the WHO:

*Those who refuse all vaccines → those who refuse but are unsure → those who accept some and refuse some, possibly delay → those who accept but are unsure, possibly questioning → those who accept all without questioning.*<sup>35</sup>

The main reasons as analysed by WHO and the UNICEF and reported by countries for vaccine hesitancy are presented below. They relate to: risk-benefit (scientific evidence), e.g. “vaccine safety concerns” or “fear of side effects”; lack of knowledge of vaccination and its importance, e.g., “lack of knowledge of parents on benefit of immunisation”; religious, cultural, gender and socioeconomic issues.<sup>36</sup> A major reason for hesitancy is fear of side effects, where the problem is that people do not place the risk in context – i.e. consider the risk of disease – and therefore do not do a proper risk-benefit calculation.

**Vaccine hesitancy around the globe: Analysis of three years of WHO/UNICEF Joint Reporting form data (2015-2017)**



<sup>35</sup> *Ibid.*

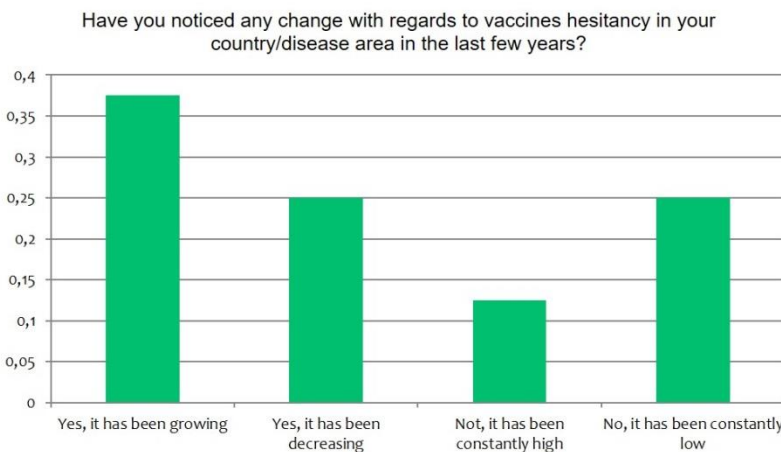
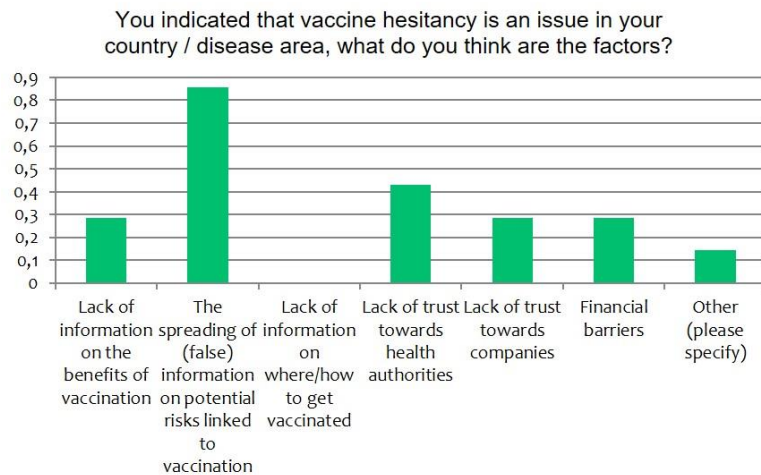
<sup>36</sup> Source: <https://www.sciencedirect.com/science/article/pii/S0264410X18304195>



The majority of reasons cited for hesitancy as reported by the countries were based on opinion, with only 38% of responses being based on assessment. This is a limitation to the scientific validity of the research. It is unclear why so few countries are carrying out assessments, given their value for tailoring interventions to better address hesitancy both at the national level and in subgroups of people. Assessments are also key for determining if an intervention has been effective in reducing overall hesitancy.

**Contextual influences** include historic, social, cultural, environmental, economic, political and institutional factors which might influence vaccine hesitant populations. One common influence identified by research are conspiracy theories, which are compounded by a lack of clear communication of the extremely low levels of risk of vaccines. Religion may also be a strong factor. Negative exposure to media is another determinant

of hesitancy, with rumours and myths about vaccines finding their way into the general media.



Attitudes towards vaccination have changed over time, but hesitancy or scepticism is not a recent phenomenon. It was already present in Jenner's time in the early 1800s. since the 1970s the problem has grown as people started thinking of their health less in terms of society and more as an individual issue, but also an increasing impression that infections were not dangerous

– that they could all be treated. Forgetting, or loosing respect for, infections is an important factor.<sup>37</sup>

Among other negative influencers the WHO SAGE Vaccine Hesitancy Working Group recognised celebrities, personal perceptions and perceptions of the individual's social environment, negative encounters with vaccine providers, feeling pressure to vaccinate, fear of needles, or pain or fear of adverse events.<sup>38</sup>

<sup>37</sup> <http://www.cbc.ca/news/canada/kitchener-waterloo/vaccination-hesitancy-parenting-decision-anti-vax-history-1.4611576>

<sup>38</sup> What influences vaccine acceptance: A model of determinants of vaccine hesitancy, [http://www.who.int/immunisation/sage/meetings/2013/april/1\\_Model\\_analyze\\_driversofvaccineConfidence\\_22\\_March.pdf](http://www.who.int/immunisation/sage/meetings/2013/april/1_Model_analyze_driversofvaccineConfidence_22_March.pdf)

## Is hesitancy an issue in the communities of patients with chronic conditions?

EPF members surveyed on the matter expressed the following main motives for delaying or refusing vaccination:

- |  |  |
|--|--|
| 1. Lack of information on vaccination benefits   | 5. Lack of trust in pharmaceutical companies |
| 2. News on potential risks (including fake news) | 6. Lack of trust in healthcare professionals |
| 3. Lack of trust in health authorities           | 7. Other                                     |
| 4. Price of vaccines                             |  |

The EPF survey on vaccination ran in March 2018 and though the response rate was limited, it still highlighted some important issues that EPF will explore further with its membership.

### ***Vaccination is a question of solidarity – Frank’s story***

*Frank, 65, was born with a rare genetic condition which affects his lungs and liver, called Alpha 1 antitrypsin deficiency, a rare form of Chronic Obstructive Pulmonary Disease (COPD), a chronic lung disease. There is only one long term treatment for Alpha 1, augmentation therapy – the use of alpha-1 antitrypsin protein (AAT) from the blood plasma of healthy human donors to increase the alpha-1 levels circulating in the blood and lungs of the patient. The therapy is administered by a weekly intravenous infusion.*

*For Frank, the question of vaccination is one of public health and of solidarity. He believes that the healthy population should help protect those living with a chronic condition. Because of his condition, Frank is vaccinated against the flu, hepatitis A and B, pneumococcus, tetanus and whooping cough.*

*A strong motivation for him are the reports from his wife, who is a gynaecologist and in her work has witnessed people falling seriously ill as a result of vaccination hesitancy.*

*Frank’s doctor (pulmonologist) prescribed him the pneumococcus and flu vaccines, and he fully trusts his doctor so would strictly follow his recommendations. He said that in one instance the flu vaccine got him “a bit low for a couple of days”, but not so that it would make him doubt the benefits of this vaccine. He regrets that the value of vaccination in general does not have the recognition it deserves, it should be part of a quality of life, multi-functional approach. Frank believes that vaccination suffers from a bad image – maybe because it goes through a needle? – and an impression that it will [negatively] affect one’s body and system. We should work on the image of the body, Frank recommended.*

*Frank finds it difficult to understand why misinformation has taken such a big importance, when statistics prove that prevention is effective. He believes that vaccination hesitancy is not based on facts and reason, but on perceptions and beliefs.*

*Frank recommends that vaccination should be the subject of a large-scale campaign of information and raising awareness on its value. Vaccination as a way to protect ourselves but also others (through sufficient coverage in the population at large) should be a part of our “normal” health values. There is work to do to instil the importance of vaccination as part of well-being and healthy life in people’s minds. It needs a radical shift of mentality that may take years and requires robust and on-going communication, with a long-term view. Actions must be taken at national and EU level too, he suggested.*

## **Addressing vaccine hesitancy in patient communities**

Although hesitancy is by no means the only barrier to uptake, it nevertheless is a factor for some patients. Strategies to address hesitancy in the general population may be useful also to address the issue in patient communities. As we have outlined, a driver of low uptake and hesitancy among patients appears to be lack of patient-oriented, evidence-based and trusted information, and/or a lack of accurate estimation of the relative benefits and risks of vaccination versus having the disease that is prevented through vaccination.

We believe there is a need to understand carefully the factors behind low uptake in specific groups of patients, and ensure appropriate information tools and resources are available to “plug” any gaps in information. In addition, given patients generally trust their healthcare

professionals and the information received from them, it is necessary to ensure healthcare professionals are trained to ensure that immunisation is part of the treatment plan of patients with chronic diseases and conditions, and that the issue of immunisation is raised during clinical encounters.

Professional training is still not sufficient; professionals do not always recognise the importance of vaccination and may not be able to answer patients' specific questions and counter their hesitations, with the right communication tools that might sway those who are unsure.

A key learning from our research and literature review is the need to pay greater attention to the reasons why a person would hesitate to be vaccinated or refuse vaccination, to address the specific determinants underlying vaccine hesitancy of the person with a chronic disease, and build the response based on this cause. Lack of vaccination uptake and hesitancy must be addressed through a dialogue and with scientific evidence.

The messenger may be more important than the message itself and trust is vital in order for people to accept health interventions. Hesitant patients may question facts and figures presented by scientists; therefore the medical community must intensify its efforts to ensure the integrity of its evidence and the consistency of messaging.<sup>39</sup>

**“There is a high level of vaccination in the HIV/AIDS population, thanks, in part, to the strong sense of community in which patients speak and share among themselves, including on the importance of vaccination.”**

*Peter, HIV-AIDS advocate, Germany*

Another element to address hesitancy is the role of parents and educators in helping children from an early age learn the skills of

critical thinking and informed scepticism to discern life-saving facts from fatal fictions – they need to be trained to form their own judgement, and the EC is supporting this approach with the inclusion of vaccine hesitancy under their work stream on “fake news”.

vaccine hesitancy must be assessed in the cultural, social and health context specific to each country, or even regions. Positive or negative influencers maybe of different kind, such as religion, and peer-pressure, such as the one expressed by Peter (right), is a key element of decision on vaccination – we often focus on media and the internet as a source of information, but the importance of information provided by people we share concerns and issues with should not be neglected. Patient organisations demonstrate their central role in acting as information providers as well as peer counsellors.

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<sup>39</sup> The discredited Andrew Wakefield was not disciplined by the UK medical authorities, nor his article retracted by The Lancet until 2010 – 12 years after being published.

## Vaccines policies and regulatory frameworks

The regulatory framework for medicines/vaccines authorisation is set up at EU level, but vaccination policies, schedules and legal rules or recommendations are a national competence, and every EU Member State has its own immunisation plan. Guidance is provided by the World Health Organization (WHO), the European Centre for Disease Control and Prevention (ECDC), the European Commission and relevant scientific and/or medical bodies, which help collect and research the latest evidence in the field, as well as monitoring, and sharing information. The WHO for instance is tasked with developing evidence-based immunisation policy recommendations through its independent advisory group, the Strategic Advisory Group of Experts (SAGE) on Immunisation, it publishes vaccine position papers providing global vaccine and immunisation recommendations for diseases that have an international public health impact<sup>40</sup> and tables for routine immunisation.<sup>41</sup>

**The European Medicines Agency (EMA)**, the European body for the authorisation and monitoring of medicines licensed in the European Union does not hold specific information on vaccination as a whole, but focuses on specific products and their safety with providing pharmacovigilance services both at individual (a patient can report an adverse event through a dedicated portal of EMA's website) and country level. Before a new vaccine is put on the market, the product undergoes very strict scrutiny from the EMA to assess quality, efficacy and safety. Vaccines will need 1. a marketing authorisation 2. registration or licencing 3. Quality assessment (for each batch of vaccines) before release, 4. post-licensure commitments / follow-up measures 5. license renewals, which under European legislations have to be submitted five years after approval.<sup>42</sup> The EMA also helps medicine developers prepare marketing-authorisation applications for human medicines with scientific guidelines on vaccines.

**The European Commission** is mainly focusing efforts on supporting and mitigating research findings, sharing best practice and helping Member States in their effort to enhance vaccination quality and quantity in their respective country. However, it also contributes to policy-making. In April 2018 the Directorate General for Health (DG SANTE) published a *Commission Communication* and a *Proposal for a Council Recommendation* titled "Strengthened co-operation against vaccine-preventable diseases."<sup>43</sup> These documents build on a number of existing EU policies and projects in the area of vaccination.<sup>44</sup>

The Communication is built around three pillars: (i) Tackling vaccine hesitancy and improving vaccination coverage; (ii) Sustainable vaccination policies in the EU; and (iii) EU coordination and contribution to global health. A number of priority activities are outlined under each area.<sup>45</sup> The Council Recommendation, which is a more political document, makes specific recommendations addressed to the EU Member States, the Commission, and both jointly. The recommendation is expected to be adopted by the Council in December 2018 with minimal alterations.<sup>46</sup>

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<sup>40</sup> Source: WHO [http://www.who.int/immunization/policy/position\\_papers/en/](http://www.who.int/immunization/policy/position_papers/en/)

<sup>41</sup> Source: WHO [http://www.who.int/immunization/policy/immunization\\_routine\\_table1.pdf?ua=1](http://www.who.int/immunization/policy/immunization_routine_table1.pdf?ua=1)

<sup>42</sup> Source: Vaccines Europe <https://www.vaccinesurope.eu/about-vaccines/eu-regulatory-framework-for-vaccines/>

<sup>43</sup> Source: DG SANTE, 26 April 2018 [http://europa.eu/rapid/press-release\\_IP-18-3457\\_en.htm](http://europa.eu/rapid/press-release_IP-18-3457_en.htm) and [https://ec.europa.eu/health/sites/health/files/vaccination/docs/com2018\\_2442\\_en.pdf](https://ec.europa.eu/health/sites/health/files/vaccination/docs/com2018_2442_en.pdf)

<sup>44</sup> Including the 2009 Council Recommendation on seasonal influenza vaccination and the Joint Procurement Agreement, established by the serious cross-border health threats Decision (1082/2013/EU), as well as the 2014 Council conclusions on Vaccinations as an effective tool in public health, the latter available at [https://www.consilium.europa.eu/uedocs/cms\\_Data/docs/pressdata/en/lsa/145973.pdf](https://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/lsa/145973.pdf)

<sup>45</sup> Communication available in all EU languages at <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2018:245:FIN>

<sup>46</sup> The proposal for a Council recommendation is available in all EU languages at <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2018:244:FIN>

**The European Parliament** adopted a Resolution in April 2018 on “Vaccine hesitancy and drop in vaccination rates in Europe”, which asks Member States and the Commission to take various actions, including awareness-raising campaigns among healthcare professionals and for patients to have the information about vaccines to take informed decisions.<sup>47</sup>

An **EU Joint Action on vaccination** (EU-JAV), a project co-funded by the European Health Programme 2014-2020 started at the beginning of September 2018 and addresses vaccine hesitancy amongst other topics. There will be 3 million of EU co-funding, 20 countries will take part (among them 17 EU Member States), with the involvement of ECDC, EMA, WHO, and the European Commission. The Joint Action will map best practices and analyse barriers and enablers behind high and low vaccination coverage rates; it will set-up monitoring infrastructures to conduct real-time public vaccines confidence monitoring; and it will provide guidance on evaluating the impact of interventions to address vaccine hesitancy. EPF is part of the stakeholder forum of this Joint Action.

**The European Centre for Disease Prevention and Control** (ECDC) works together with the European Commission, WHO and various sub-groups such as the European Observatory on Health Systems and Policies. Its role is to strengthen the capacity of the European Union Member States to protect human health through the prevention and control of infectious diseases, based on robust evidence and high-quality technical support. ECDC is the hub of European communicable disease surveillance and an exceptional source of data<sup>48</sup> but does not act as a regulator. For instance, the ECDC collects information from Member States about influenza vaccination for people with chronic diseases.<sup>49</sup> The ECDC supports and promotes a yearly European Immunisation Week every April, providing communication means, facts and figures as well as helping Member States in their effort to reach out to their citizens. The ECDC publishes the “Vaccination scheduler” with all vaccines schedules in the countries of the EU. It also presents pandemic and specific per disease (influenza, hepatitis, measles and rubella for instance) figures as well as preparedness plans.

EU research programmes, including its public-private partnership Innovative Medicines Initiative (IMI) as well as the ECDC, are supporting a number of projects in the fields of vaccine hesitancy, monitoring and communication. For instance, the E-COM@EU project focuses on “Effective Communication in Outbreak Management: development of an evidence-based tool for Europe”; the ADVANCE initiative is developing a system that will rapidly provide the best available scientific evidence to help health professionals, regulatory agencies, public health institutions, vaccine manufacturers and the general public make more informed decisions on benefits and risks of marketed vaccines. The role of the ECDC in implementing a network of sentinels across Europe will be fruitful, particularly if its major task is to capture vaccine specific concerns, geographical trends, and differences in populations. In parallel to developing new metrics and monitoring them, restoring trust and credibility of the institutions involved with vaccinations must take centre-stage.

### **Vaccination plans**

To address the need to protect their populations from infectious disease that are preventable through vaccinations, countries may have adopted immunisation plans, with or without mandatory vaccines. However, there is no easily accessible repository of all EU national immunisation plans to our knowledge.

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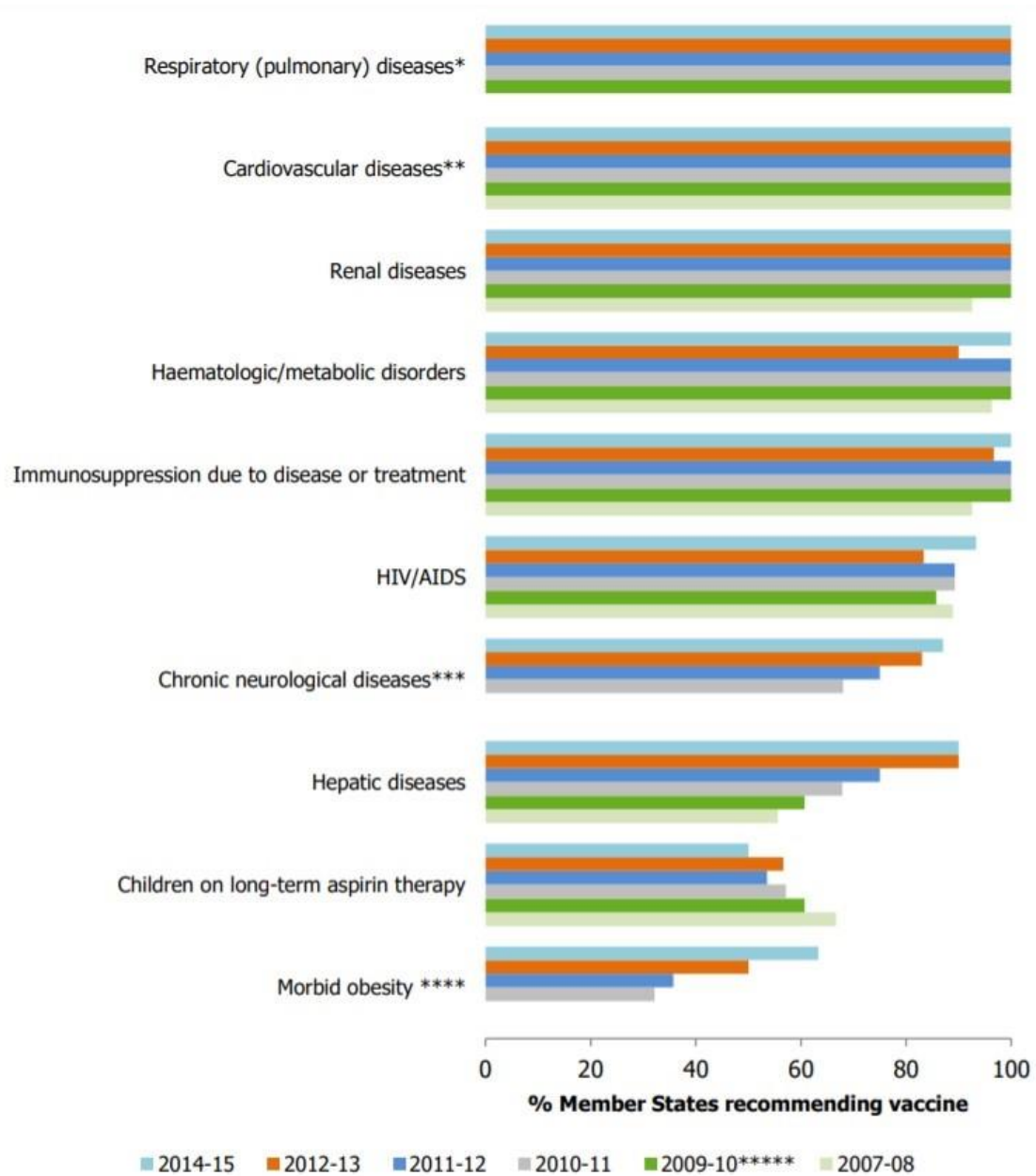
<sup>47</sup> The resolution, adopted on 19 April 2018 is available at <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2018-0188+0+DOC+XML+V0//EN>

<sup>48</sup> Source : <https://onlinelibrary.wiley.com/doi/full/10.1111/1469-0691.12430>

<sup>49</sup> Source : ECDC <https://ecdc.europa.eu/sites/portal/files/documents/influenza-vaccination-2007%E2%80%932008-to-2014%E2%80%932015.pdf>

Immunisation policies and plans for adults in the EU vary significantly across Europe, with differences in funding mechanism across Member States. For example some vaccines in some countries are offered for free universally, some for free to risk groups only, some not funded by the health authority, not reimbursed or available only out-of-pocket.<sup>50</sup>

**Proportion of EU Member States recommending seasonal influenza vaccine by chronic medical condition, 2007/08 to 2014/15 influenza seasons (ECDC data)**



<sup>50</sup> Karam Adel Ali and Lucia Pastore Celentano, "Finding the balance in life-course vaccination". EuroHealth, Vol.22 no.3, p.29. <https://www.ehfg.org/fileadmin/downloads/21-press/2016/Eurohealth-volume22-number-3-2016.pdf>

## Recommendations

We have identified broadly two categories of patients:

- (1) Those who are not being correctly advised to be vaccinated and take extra protection for their chronic illness, and
- (2) Those who do receive adequate information but still hesitate or refuse vaccines.

To address the concerns of the first group is the main focus of this initiative. EPF will provide patient organisations with several different tools to support their efforts.

### *Key recommendations*

1. Robust, evidence-based information that enable people to understand and contextualise the benefits and risks of vaccination should be made available specifically targeted towards patients with chronic conditions. This should be developed in collaboration with patient organisations.
2. More detailed knowledge is needed to understand the factors contributing to low uptake in specific patient communities, also in different countries, to better address them and tailor actions accordingly.
3. Healthcare professionals should incorporate routine assessment of their adult patients' vaccination needs during all clinical encounters to ensure patients receive recommendations for needed vaccines and are either offered needed vaccines or referred for vaccination.
4. Healthcare professionals should be trained on the importance of vaccination and armed with the relevant scientific facts to help them communicate with patients and reinforce a trust relationship.
5. the quantity as well as the quality of the information on vaccination need to be carefully assessed to be able to respond to coordinated actions against vaccination and respond with the same level of engagement and resources – including human, financial and the use of adequate communication tools,
6. Low uptake of vaccination and hesitancy within healthcare professions needs to be tackled.
7. National institutions and authorities should initiate collaborations with patient organisations to better understand their communities' needs and to formulate more effective strategies.
8. Vaccination should be regarded as a public health priority, not only for children but for adults living with chronic diseases, with a long-term vision and action plan aiming to change society's perception on vaccinations. Patient organisations should be seen as natural allies in such efforts and invited as partners in joint activities.
9. In countries where patients hold a social security card, their vaccination schedule should be included in the card.
10. A vade-mecum on vaccination could be developed specifically for patients with (specific) chronic conditions.

### *Ideas for patient organisations*

The following elements should form part of a multi-component approach to address low take-up of vaccination in chronic disease patients. Patient organisations can be well placed to address several of these recommendations, if possible working together with other stakeholders.

<b>Messenger</b>	Who is the best positioned to speak with the patient: a physician or other professional (trust, “white coat” effect), another patient, an organisation of patients, family member or a friend, a health authority. There is no single “rule” and it is worth exploring different avenues.
<b>Modes of communication</b>	Oral: share a testimony, experience, tell a “story”, interviews. Written: social media (Facebook, Twitter, Instagram, YouTube, etc.), blogs, media, flyers, brochures, billboards, posters, leaflets, in easy to understand and accessible vocabulary, including from patient groups, whose role is often to translate scientific findings into accessible information for patients.
<b>Content of the information/Quality</b>	Facts and figures, positive and negative – tell the truth, risks and benefits Comparisons: with absence of vaccination, with other risks (diseases), with side effects of other interventions such as medicines.
<b>Location of the information</b>	At the doctor’s surgery, at a local authority (town hall etc.), on the internet: national health authority website, social security or health insurance provider, dedicated vaccines information website (repository of facts and figures) patient associations, etc.  On social media, verified accounts, in the press.
<b>Quantity of information</b>	The same (evidence-based) piece of information should be repeated in a coherent way many times, both proactively and reactively (as a response to anti-vaccination campaigns or claims). The response should be proportionate enough to the volume of attacks.
<b>Source of information</b>	Scientifically validated studies (from academia), Unbiased and transparent source, International and national authorities, Health specialist press quoting peer-reviewed scientific research
<b>Access to/price of vaccination</b>	Vaccines part of the clinical guidelines to treat patients with a chronic disease could be available for free, offered by the HCP regularly communicating with the patient, in an easily accessible location: at the pharmacy, for instance.



## References, sources of information and further reading

Please note this section is up-to-date at the date of writing of the report. This is a selection of articles and documents if you wish to learn more. Among the following selection, there are key documents from the European Commission, the European Centre for Disease Prevention and Control (ECDC) and the WHO.

### General information on vaccination and vaccines:

1. WHO Europe, *European Vaccine Action Plan 2015-2020, 2015* – [LINK](#)
2. WHO Europe centralized information system for infectious diseases (CISID) - [LINK](#)
3. *Vaccine-preventable diseases briefing page* – [LINK](#)
4. Vaccines schedule - [LINK](#)
5. *European Commission Communication on strengthened cooperation against vaccine preventable diseases* - [LINK](#)
6. *Council recommendation on seasonal influenza vaccination (in particular, for at risk population)* - [LINK](#)
7. *Council of the European Union, Council conclusions on vaccinations as an effective tool in public health, 2014* – [LINK](#)
8. *European Commission, Working Document – State of play on implementation of the Council Recommendation of 22 December 2009 on seasonal influenza vaccination, 2014* – [LINK](#)
9. *EMA’s scientific guidelines on vaccines* - [LINK](#)
10. *Mandatory and recommended vaccination in the EU, Iceland and Norway: results of the VENICE 2010 survey on the ways of implementing national vaccination programmes* - [LINK](#)
11. Vaccines Europe, the EU regulatory framework for vaccines – [LINK](#)
12. How close are countries of the WHO European Region to achieving the goal of vaccinating 75% of key risk groups against influenza? Results from national surveys on seasonal influenza vaccination programmes, 2008/2009 to 2014/2015 - [LINK](#)

### Vaccination hesitancy, absence of vaccination of people living with a chronic disease

13. WHO European Technical Advisory Group of Experts on Immunization (ETAGE) - [LINK](#)
14. *Report of SAGE working group on vaccine hesitancy* - [LINK](#)
15. *Measuring vaccine hesitancy: The development of a survey tool (SAGE group)* - [LINK](#)
16. WHO Europe Guide to Tailoring Immunisation Programme (TIP) - [LINK](#)
17. Vaccine hesitancy around the globe: Analysis of three years of WHO/UNICEF Joint Reporting Form data-2015–2017 - [LINK](#)
18. What influences vaccine acceptance: A model of determinants of vaccine hesitancy - [LINK](#)
19. *Vaccine Hesitancy webpage* - [LINK](#)
20. *Let’s talk about hesitancy* – [LINK](#)
21. *Catalogue of interventions addressing vaccine hesitancy* - [LINK](#)
22. Seasonal influenza vaccination in Europe Vaccination recommendations and coverage rates in the EU Member States for eight influenza seasons 2007–2008 to 2014–2015 - [LINK](#)
23. Conducting health communication activities on MMR vaccination - [LINK](#)
24. *Vaccine acceptance or refusal?: Individual choice vs societal needs or My risks vs “our” risks* – EMA, [LINK](#)
25. *Vaccine Confidence Project, Website* – [LINK](#)
26. *Vaccine Confidence Project, The State of Vaccine Confidence 2016, 2016* – [LINK](#)
27. *Determinants of Refusal of A/H1N1 Pandemic Vaccination in a High Risk Population: A Qualitative Approach* - [LINK](#)
28. *The State of Vaccine Confidence 2016: Global Insights Through a 67-Country Survey* – [LINK](#)

29. Consenso sobre la vacunación anti-neumocócica en el adulto por riesgo de edad y patología de base (Spanish, *Consensus on anti-pneumococcal vaccination in the adult due to risk of age and basic pathology*) - [LINK](#)
30. Determinants of Refusal of A/H1N1 Pandemic Vaccination in a High Risk Population: A Qualitative Approach - [LINK](#)
31. Innovations in communication: the Internet and the psychology of vaccination decisions - [LINK](#)
32. Information on vaccination: meeting the needs of unvaccinated youngsters in the Netherlands - [LINK](#)
33. Politics, not parenting, to blame for 'vaccination hesitancy' - [LINK](#)
34. The Autism-Vaccines Myth: The Impact of the Media - [LINK](#)

### **Vaccination and people living with a chronic disease**

35. CDC webpage: misconceptions about seasonal flu and flu vaccines- [LINK](#)
36. CDC webpage Diabetes Type 1 and Type 2 and Adult Vaccination - [LINK](#)
37. HIV and Immunisation - [LINK](#)
38. *Cancer Research UK : Immunization and chemotherapy* - [LINK](#)
39. ECPC and ESMO Patient Guide Survivorship – [LINK](#)
40. Influenza Vaccination as Secondary Prevention for Cardiovascular Disease - [LINK](#)
41. EU Manifesto on influenza vaccination, our response to the burden of influenza in Europe, EFA - [LINK](#)
42. European Lung Foundation: Vaccination and Lung diseases - [LINK](#)
43. The Lancet, Rapid response to HPV vaccination crisis in Ireland – [LINK](#)
44. Annual public health and economic benefits of seasonal influenza vaccination: a European estimate - [LINK](#)
45. ESWI, The role of primary care physicians in preventing influenza (influenza vaccination of people with diabetes) - [LINK](#)
46. Association AVNIR (France) : Associations VacciNation Immunodéprimées Réalité (*association on the vaccination of immune-depressed people & reality*)- [LINK](#) and Meeting report “Vaccination des adultes à risque : les associations prennent la parole” (*vaccination of people at risk: associations speak up*) - [LINK](#)
47. Alliance du Coeur (France, *association of patients with cardio-vasculaire diseases*), brochure : « Vaccins... Pourquoi on ne peut pas s’en passer » (*vaccines : why we cannot do without*) - [LINK](#)
48. Association Nationale de Défense contre l’Arthrite Rhumatoïde (ANDAR) France (*national patients association of defence against arthritis rheumatoid*): « Vaccinations et polyarthrite rhumatoïde : Mythes et réalités », (*vaccination and polyarthrititis rheumatoid, myths and reality*) - [LINK](#)
49. France Rein (*Kidney France, patients association*) : La Vaccination utile et nécessaire ! (*vaccination, useful and necessary*) - [LINK](#)
50. Osservatorio Epidemiologico Regione Puglia – (Italian, *The epidemiological observatory of the Puglia Region*) : « Vaccini: un vademecum contro la disinformazione Le 58 risposte agli antivaccinisti: un vademecum contro la disinformazione » (*Vaccines, a vademecum against mis/disinformation*) - [LINK](#)
51. Vacunación en la población adulta de riesgo (Spanish, *vaccination for the at risk population*) - [LINK](#)