European active citizens for vaccination: focus on Poland (2019 - 2020)



Grupa Fokusowa na temat strategii szczepień w okresie całego życia





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ENTING FOR LIFE

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1. About us

Cittadinanzattiva APS has more than 40 years of experience in protecting citizens' rights in the health sector, which initiated with its Tribunale per i diritti del malato¹ ("Tribunal for Patients' Rights" or TDM) in 1980 and was later strengthened through the Coordinamento nazionale Associazioni Malati Cronici² (National Coordination Centre of Chronic Patients' Associations) in 1996.

Cittadinanzattiva promotes protection against violations of the right of individual citizens through its free-of-charge counselling, information and support service provided by 300 TDM offices located nationwide. Each year in Italy, we collect an average of 25,000 among complaints and requests of information from patients and citizens and thanks to them, we present different Annual Reports to the Ministry of Health and relevant healthcare stakeholders, providing them a civic point of view about the daily relationship between the National Health System and Italian citizens and describing the state of the art of the access to health services in the different Italian regions.

Starting from 2001, through its EU branch, Active Citizenship Network (ACN)³, Cittadinanzattiva has been promoting civic participation and rights' protection, also at European level, gathering almost 200 civic and patients' organizations all over the Continent. **Active Citizenship Network (ACN)** is a flexible network of European civil society organizations that participate as partners in different projects, aimed at encouraging the active participation of citizens in the European policies. ACN mirrors Cittadinazattiva's policies concerning healthcare, consumer protection, corporate and social responsibility, education and training at international level. ACN's mission is to promote and support the construction of European citizenship as an active citizenship, meaning the exercise of citizens' powers and responsibilities in policymaking. The European Charter of Patients' Rights and promotion of the European Patients' Rights Day are its major initiatives in the field of health.

Over the last 20 years, it has been increasing Cittadinanzattiva - Active Citizenship Network contributions for the promotion and protection of citizens' rights in the fields of vaccination.

¹ https://www.cittadinanzattiva.it/corporate/salute/1843-tribunale-per-i-diritti-del-malato.html

² https://www.cittadinanzattiva.it/corporate/salute/1845-cnamc-malati-cronici.html

³ www.activecitizenship.net

2. Our commitment on Vaccination

Cittadinanzattiva -Active Citizenship Network is deeply committed to contribute to raise awareness about the importance of vaccination in Italy and across Europe⁴: immunization is vital to prevent diseases and protect life. Our commitment has been appreciated by the European Center for Disease Prevention and Control (ECDC), the Agency of the European Union aimed at strengthening Europe's defense against infectious diseases that, in 2016, has decided to officially include Cittadinanzattiva in the ECDC Technical Advisory Group for Increasing Vaccine Coverage. As members of this Advisory Group we feel a great responsibility to commit ourselves to this issue: we believe that a widespread vaccination culture is necessary, particularly to overcome the idea that we only get vaccinated when we are young and, instead, to shift to a common knowledge linked to a life-course vaccination approach which prevents a series of diseases even during adulthood.

Some example of our activities:

In 2018 *#Rompilatrasmissione* (break the broadcasting), an information campaign on vaccination was held in Italy by Cittadinanzattiva-Tribunal for patients' rights. Its aim was to illustrate citizens the benefits of prophylaxis through correct, scientific and evidence-based information in a more friendly environment of organizations that deliver vaccines across Italy⁵.

On November 16, 2018, an "Open day"⁶ took place in 37 cities of eleven Italian regions: Cittadinanzattiva-Tribunal for Patients' Rights local offices opened to give information on vaccines and help citizens to face any critical issues in this area. Activists and experts met



citizens to promote proximity information, distributing useful material and collecting reports in order to offer tools and support to protect themselves.

⁴ http://www.activecitizenship.net/patients-rights/projects/278-the-engagement-of-cittadinanzattiva-on-vaccination.html

⁵ https://cittadinanzattiva.it/files/progetti/salute/RompiLaTrasmissione_WEB_12_09.pdf

⁶ https://www.cittadinanzattiva.it/primo-piano/salute/11823-16-novembre-primo-open-day-sui-vaccini.html

A series of training initiatives titled "Vaccinations, rights and duties today: learn to teach and to promote empowerment"⁷ were launched by Cittadinanzattiva on the 22nd of October 2019. The goal of the initiative was to improve the understanding of vaccination among constituencies and activists.

On the 23rd of October 2019, Cittadinanzattiva launched in Italy the second edition of its #Rompilatrasmissione focused on flu vaccination⁸.

On the 28th February 2018, ACN realized a public event in the European Parliament, hosted

by the MEP David Borrelli in the framework of the MEPs Interest Group "European Patients' Rights & Cross-Border Healthcare". The event titled "The challenges of life-course vaccination to enhance public health protection in Europe: a multi-stakeholder approach"⁹—intended to demonstrate what citizens and advocacy

groups, in partnership with stakeholders can offer in terms of raise awareness about the phenomenon, enhance the body of knowledge of positive cases and success, and strengthen commitment to this topic.

On the 7th November 2018, ACN organized another event at the EU Parliament aimed to build

a close collaboration with European institutions and health-stakeholders to determine how we can work together to a more effective civic society engagement in vaccination policies. The event brought together MEPs, the Deputy Director General of DG SANTE, the leader of the Joint Action on Vaccination, experts and of course representatives of civic society very active on the theme of vaccination¹⁰.



Vaccinazione Antinfluenzale





ts campaign on vaccination called

⁷ https://www.cittadinanzattiva.it/comunicati/salute/12671-vaccinazioni-diritti-e-doveri-oggi-in-italia-al-via-i-seminari-di-formazione.html

⁸ https://www.cittadinanzattiva.it/files/progetti/salute/rompilatrasmissione_2019_DEFINITIVA_WEB.pdf

⁹ http://www.interestgroup.activecitizenship.net/131-the-challenges-of-life-course-vaccination-to-enhance-public-health-protection-in-europe-a-multi-stakeholder-approach.html

¹⁰ http://www.activecitizenship.net/gallery-home/275-active-citizens-in-europe-advocate-for-vaccination-encouraging-reactions-from-european-institutions.html

3. Project description "European Active Citizens for Vaccination"

In April 2019 ACN launched, during the European immunization week, a new project called **"European Active Citizens for Vaccination"**¹¹. The aim was to improve the awareness on the importance of vaccination across Europe: the scientific evidence is clear, vaccination is an essential public health tool and helps to guarantee our fundamental rights as a European citizen.

ACN, realized two main actions:

 A social media communication campaign throughout a Video that supports and spread this core message: "Together, as active and aware citizens, we can protect ourselves, become the champion of your future!", sending a unified, clear and strong message on the importance of vaccination directly from citizens to citizens. Videos were made in all the national languages of the involved countries (Italy, Hungary, Poland, Ireland and Spain) and then produced, shared and customized for each country. Moreover, an informative leaflet in a different language has been produced¹².



Polish video



Some parts of the Polish informative leaflet

¹¹ http://www.activecitizenship.net/patients-rights/projects/294-european-active-citizens-for-vaccination-2019.html

¹² All the materials are available on www.activecitizenship.net/patients-rights/projects/294-european-active-citizens-for-vaccination-2019.html

2. A civic consultation of the national immunization plans throughout the realization of three focus groups in Spain, Hungary and Poland titled "Civic Consultation on the National Immunization Plan: is it "focused on a life course approach?": thanks to the work and cooperation of our constituency of national citizens' organizations, we brought together around the table leaders of civic and patients association, healthcare professionals, policymakers and other stakeholders involved in each country in the administration of vaccines. The aims was find together proposals and gather impressions, suggestions, advices and provide institutional and health care stakeholders with: the strengths/weaknesses of national policies and plans about their approach to life-course immunization approach; the common elements or specificities that affect a greater or lower success of this approach. The first countries involved were Hungary, Poland, Spain with the respective associations: Vedem Civilian for Vaccination¹³, Institute of Patients' Rights and Health Education¹⁴, Foro Español de Pacientes¹⁵ and the Asociación Española contra la Meningitis¹⁶.



A glimpse of the Polish focus group.

¹⁵ https://forodepacientes.org/

¹³ https://vedem.hu/

¹⁴ http://ippez.pl/

¹⁶ https://www.contralameningitis.org/la-asociacion/

For the success of the project, ACN established and managed a Steering Committee, composed of professionals, experts, and representatives of civic and patients' associations to define the messages of the social media communication campaign and the main contents of the civic evaluation. The meeting of the Steering Committee of the project was realized in Brussels at the beginning of July 2019. The members involved were:

George Griffin	Federation of European Academies of Medicine (FEAM)	
Professor Alberto Tozzi and Dr. Sara Ciampini	Epidemiologist and Chief Innovation Officer, Bambino Gesù Children's Hospital, Italy Leader of the Vaccine Safety Net Web Analytics project.	
Elena Moya	Confederation of Meningitis Organizations (CoMO)	
Dafne Holt and Malcom Taylor	Coalition for Life-course Immunization	
Silvia Romeo	ThinkYoung	
Gary Finnegan (<i>Moderator of the discussion and media partner</i>)	Vaccines Today	
Mariano Votta, Daniela Quaggia, Alessandro Cossu, Andrea Falzarano	Cittadinanzattiva - Active Citizenship Network	

The key role of the life-course approach in vaccination policy

Most vaccination programmes focus on discrete life stages such as childhood, but evidence supports a life-course approach, meaning vaccination given through all phases of life. The life-course approach to immunization recognizes the role of immunization as a strategy to prevent disease and maximize health over one's entire life, regardless of an individual's age. A life-course approach requires that immunization schedules and access to vaccination respond to an individual's stage in life.

A life-course approach has been advocated by the World Health Organization (WHO) as a model of healthcare provision that would benefit both individuals and healthcare systems. It involves looking at health as a continuum through life: a dynamic and interconnected process, as opposed to rigid life stages. It moves away from traditional approaches, where one develops and delivers vaccines in response to immediate threats for discrete age groups. Instead, investments in vaccination strategies should be based on their potential to strengthen individuals' ability to maintain good health over the course of their lives, and their impact on the prevention of other pathogens and comorbidities over time

3. Methodology applied in the Civic Consultations (Focus Group)

ACN worked on the creation of a questionnaire (with both closed and open questions) that was handed out to each participant in order to be used as a base of discussion during the focus group on the specific theme of life-course immunization approach in the national immunization plan; to make an exchange of information on how it is organized in that country compared with other countries: to find together proposals, suggestions, advice on that aspect.

Different people were involved, such as: leaders of civic and patient's associations, healthcare professionals, policymakers and other stakeholders implicated in the administration of vaccines. Each focus group was led by a moderator and lasted between one and a half to three hours, depending on the number of participants. The discussions were recorded in order to be better summarized. Each participant was given two sheets with the written questions that the moderator had to ask during the discussion so that they could always see them and write down their answers in a completely anonymous way. During the debate they were given post-its of different colours to indicate their answer to the questions in a poster in the middle of the table, from which the moderator got inspiration to guide the next discussion.

The questions were divided into two blocks, A and B: in part A, the more general, all participants were asked to answer how they evaluated the awareness and support for lifecourse immunization approach in their Country, among different subjects, and how much vaccination plan in their country is designed to help maximize the individuals' ability to protect themselves from infection over the course of their lives.

In part B, the questions regarded five key policy elements that characterize effective lifecourse immunization strategies (according to the IFPMA Report¹⁷):

- 1. Comprehensive immunization program that supports vaccine availability,
- 2. Public demand for immunization,
- 3. Engaged healthcare professionals,
- 4. Multidisciplinary and cross-sectoral coordination,
- 5. Robust data informing policies and programs.

¹⁷ https://www.ifpma.org/wp-content/uploads/2019/08/IFPMA HPP Life Course Immunization Full Report.pdf



Image from IFPMA report

5. Main results in Poland

The Polish Focus group took place in Warsaw, in the National Aids Centre, on 12th December 2019. The meeting was organized by the Institute of Patients' Rights and Health Education. The participants were:

Grzegorz Błażewicz	Deputy Patient Ombudsman
Dr Marek Posobkiewicz	Chief Sanitary Inspector of the Ministry of the Interior and Administration, former Chief Sanitary Inspector of the country
Andrzej Kuczara	President of Aby Żyć Foundation
Beata Zawada	Pediatrician
Jerzy Gryglewicz	Lazarski University, Public Health expert
Igor Grzesiak	Vice-chairman of the Institute for Patient Rights and Health Education (<i>Fundacja Instytut Praw Pacjenta i</i> <i>Edukacji Zdrowotne</i> j)
Marta Kulpa	Institute for Patient Rights and Health Education
Patrycja Rzucidło-Zając	External affairs Director, Institute for Patient Rights and Health Education
Aleksandra Kurowska (Chairman)	Medical journalist, editor-in-chief of the portal about the healthcare system
Daniela Quaggia (Observer)	Active Citizenship Network

The participants started answering the question (A.1) regarding their perception of the **awareness and support on life-course immunization approach among citizens**, showing how most of them believed that it is *poor*, one believes it is *very poor*, only one believed it is

acceptable and just one more that it is good.

Very Good	Good	Acceptable	Poor	Very Poor
0	1	1	5	1

About **awareness and support among health professionals (question A.2)**, most of the answers rated it as *acceptable*. Two participants think it is *good* and one that it is *poor*.

Very Good	Good	Acceptable	Poor	Very Poor
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¹⁸ We inserted an emoticon next to each answer as a visual summary of the main result, ed.

0	2	5	1	0

Concerning **awareness and support among health authorities (question A.3)**, most of the participants think it is *acceptable*. Two consider it *good* and two that it is *poor*.

Very Good	Good	Acceptable	Poor	Very Poor
0	2	4	2	0

For what concerns **policy maker's awareness and support (question A.4)**, utmost considers

it as *poor*. One as *good* and three as *acceptable*.

Very Good	Good	Acceptable	Poor	Very Poor
0	1	3	4	0

Finally, participants believe that awareness and support among civic and patients'

associations (question A.5), is *good*. Three consider it *acceptable* and one *poor*.

Very Good	Good	Acceptable	Poor	Very Poor
0	4	3	1	0

Regarding the vaccinations plan and its capacity to maximize the individuals' ability to protect themselves from infection over the course of their lives (question A.6), nearly all

participants believe it is well designed. Though three believe, it is not. \heartsuit

YES	NO
5	3

The eight participants then discussed the second part of the questionnaire.

Answering about how the development of a **immunization schedule that covers whole life course** is in their country **(question B.1)**, most participants said that it is *in development,*

two that it is *well developed* and one that it is *not yet developed*.

Well Developed	In development	Not yet developed	No Answer
2	5	1	0

Concerning the existence of **recommendations** in national immunisation programme for patients with specific **chronic conditions (question B.2)**, five participants answered it is *well*

developed. Two that it is *in development* and one *not yet developed*.

Well Developed	In development	Not yet developed	No Answer
4	2	1	1

Participants also believe that **awareness campaigns encouraging vaccine uptake across the life course** in their country **(question B.3)**, are *in development*. Except one that defined it has

not yet developed. 😐

Well Developed	In development	Not yet developed	No Answer
0	7	1	0

About the involvement of Active Civil society organizations in vaccine promotion (question

B.4), most of the participants answered that it is *in development*. One that it is *well developed*

and two that it is *not yet developed*.

Well Developed	In development	Not yet developed	No Answer	
1	5	2	0	

On the aspect of health care professionals' education and training about benefits of immunization across the life course (question B.5), half of the participants answered that it

is *in development*, two that it is *well developed* and two that it is *not yet developed*.

Well Developed	In development	Not yet developed	No Answer
2	4	2	0

Talking about the support activated to facilitate **Health Care professionals to be vaccinated** (question B.6) five participants answered this option is *in development*. One that it is *well developed* and two that it is *not yet developed*.

Well Developed	In development	Not yet developed	No Answer
1	5	2	0

For what concerns **immunization integrated into healthy ageing policies (question B.7)** (national health and ageing policies that recognize immunization as an important strategy to achieve their aims), most participants answered it is *in development*. One that it is *well developed* and two that it is *not yet developed*.

Well Developed	In development	Not yet developed	No Answer
1	5	2	0

On vaccine delivery in non-clinical settings (question B.8), most participants answered that

it is *not yet developed*. Three answered it is *in development*.

Well Developed	In development	Not yet developed	No Answer
0	3	5	0

About the existence of a definition of **coverage targets for vaccines in all groups across the life course (question B.9)** to evaluate immunization program effectiveness and, determine whether new initiatives are required in Poland, nearly all participants answered it is *in development*. Just one that it is *not yet developed*.

Well Developed	In development	Not yet developed	No Answer
0	7	1	0

Regarding the last question on **timely and accurate data on vaccine uptake (question B.10)**, most participants answered that this aspect is *in development*. Two that it is *not yet developed*.

Well De	veloped	In development	Not yet developed	No Answer
0		6	2	0

6. Elements emerged from the debate

The vaccination system in Poland is generally evaluated as good, but not very good. All participants agreed that it requires some changes. Some of the actions are already being implemented, but not to the extent expected.

The advantages of the Polish system mentioned in the discussion, among others, were:

- the State budget covering expenses for vaccinations making them accessible independently of the patient's financial situation;
- mandatory vaccination for children & immunization card (increasingly required in schools) which is stored at the general practitioner's office and used to monitor progress through the immunization schedule;
- activities of some of the local governments, including information campaigns and financing of vaccinations that are not refunded (e.g. for children and seniors);
- the large and growing **role of non-governmental organizations** in promoting vaccination

Implemented changes:

- activation of the **Chief Sanitary Inspector**, who more widely encourages vaccination and takes actions against anti-vaccination movements.
- planning **changes in the vaccination calendar** to increase vaccine availability in other areas such as HPV.
- if public funds are not enough to cover complete costs for vaccination a partial **reimbursement** could still be offered.
- decisions of some local governments to give preference for vaccinated children in the **recruitments to kindergartens** (education at school is compulsory and free, but in public kindergartens, e.g. due to lack of places, additional criteria are introduced).

Challenges:

- Vaccinations in Poland are mainly associated with the childhood period, there is **no comprehensive life-long vaccinations** information or programmes.
- **insufficient attention to vaccines for adults**, including immunization against influenza, tetanus, tuberculosis, etc. These are not given the same focus as vaccination of children, even though, especially in seniors, infectious diseases can be life-threatening

- too few vaccines are reimbursed, which means that, for example, recommended but not covered by the State vaccines against rotavirus, chickenpox or HPV are only available for selected individuals and thus there is no possibility of achieving population immunity;
- defining some vaccines as recommended (meaning not reimbursed) means that patients and their relatives often misinterpret them as less needed, and therefore to be omitted;
- the lack of a comprehensive understanding by public authorities on health care expenditure and indirect costs - significant amounts spent on treating diseases that can be vaccinated against what would generate savings within few years;
- not easy access to vaccination due to organization issues: in many cases, after qualification for vaccination, you must go to the pharmacy to get the vaccine, and then again go back to the clinic. These are difficulties that discourage vaccinations;
- **waiting lists** for vaccinations appointments can be quite long and once you have your appointment you may not be able to get the shot due to health conditions etc.
- lack of update knowledge on vaccinations among physicians and representatives of other medical professions. It happens that they discourage vaccinations, or they are not sure who are the addressees of vaccines and when etc;
- public media too little involved in the promotion of vaccinations;
- **vaccination of medical staff**, among others against measles: currently, the regulations and interpretations regarding vaccinations and who should pay for them are unclear.
- availability of vaccines since many of the recommended vaccines are not mandatory, the Polish market is not a priority for producers and vaccines production is not as fast as the production of chemical substances. In the case of vaccines against HPV, rotavirus or even measles (for adults, because for children they are guaranteed), there are big problems and even weeks of interruptions in the availability of preparations occur.
- **clear regulations** there are currently different interpretations regarding whether public clinics can have and offer non-mandatory vaccines provided by the health-epidemiological stations. Some public clinics give up their distribution, making life difficult for patients. An unclear issue is whether a medical facility may charge a fee for a vaccine (whether this is not a retail sale of a medicinal product, which is the job of pharmacies).

During the debate some other considerations emerged such as the importance of **health education** from an early age through a lifetime.

Another important point regarded designing and implementing **pharmaceutical care**, which would include performing at least some of the vaccinations at the pharmacy, without the necessity to visit a doctor: access to pharmacies is much simpler. This direction is being developed in other countries, in Poland it has been discussed, but the ministerial project on pharmaceutical care does not contain this element. It was included, though, in the National Drug Policy for the years 2018-2022.

A wider involvement (and financial incentives) to, first of all, **nurses** – that now can perform vaccinations, but cannot qualify or prescribe them - and other different heath care professionals, such as midwives, would make access to vaccines and information much easier, also lightening the heavy workload, and the lack, of doctors.

Vaccination efficiency assessment - selection of the most effective preparations if the differences in price are not large. One of the reasons why are there doubts around vaccines is e.g. the choice of vaccines with a narrower scope of activity for a given population, due to the lower price. Many parents do not **trust** the choice of MoH and vaccinate children at their expense, e.g. against pneumococci.

Considerations and advices about funds and economic incentives:

- adopting an adequate resolution of the Council of Ministers the National Program for Preventing Infectious Diseases - which would ensure a stable funding and expand the scope of free vaccinations. In fact, according to the recommendations of the European Commission, mechanisms should be introduced to ensure that the expenditure on vaccines amounts at least to 0.5% of public expenditure on health care because vaccinations are an investment.
- change in vaccines funding: now vaccinations are carried out as part of primary healthcare. Primary healthcare physicians are remunerated with a capitalization rate
 a specific amount for the entire year - independently of the number of services performed or the cost of medical exams. One action that could increase the vaccination rate - especially for adults - is to separate vaccinations funding from the service rendered.
- incentives for employers to invest in employees who get vaccinated, or additionally their families, too (i.e. cost deductions).
- lower health premium for people who take care of their health, including those who get vaccinated (for political reasons, impossible to implement...).

 the creation of a special fund, that has been discussed and announced a long time ago, would be used to finance assistance for people who had a vaccine adverse reaction (patients would benefit from this, and furthermore offering help and admitting that vaccine adverse reactions, though very rarely, but do occur could increase confidence in vaccines, combating conspiracy theories about them).

Finally, other options discussed were about development of vaccines that do not require injection (now available against rotaviruses and for children against influenza), as less anxious for patients due to less invasiveness and therefore potentially feasible, for example, by the patients themselves.

And about a wide campaign on vaccinations that involves celebrities, using social media (that too often are used to disseminate false information).

7. The ACN' contribution on previous publications on the topic

Previous publication on vaccinations, which led to this project, were:

- "A life-course approach to vaccination: adapting European policies¹⁹".

This report has outlined the benefits and challenges about implementing a life-course approach to vaccination. A change of policies towards a life-course approach may help anticipate new health threats and develop policies that address them. By vaccinating and educating people about vaccination throughout their lives, there will be a population that has a better capacity to lead healthy, productive lives for longer. This, in turn, will contribute to the sustainability of our healthcare systems and the productivity of our societies overall, for current and future generations. For this reason, stakeholders need to come together



to implement concrete actions to ensure vaccination achieves its full potential.

- "The life-course approach to vaccination: Harnessing the benefits of vaccination throughout life²⁰."

In this article, the topic of vaccination beyond childhood was addressed. It mains outcomes show how a long life approach to vaccines brings significant benefits at the individual, community and socio-economic levels. The benefits of vaccination beyond childhood still need to be broadly understood and action must be taken by policymakers, healthcare professionals and patient and civil society organizations to ensure that the benefits of vaccination are fully realized. The Five areas of change mentioned in the



methodology chapter were defined and the need to ensure vaccination across the life-course in national immunization programs came out. This included investing in robust data collection and analysis; ensuring coordinated, multidisciplinary leadership from the top; engaging healthcare professionals; changing public perceptions of vaccination; and integrating vaccination into schools and workplaces.

¹⁹ http://interestgroup.activecitizenship.net/files/news-and-events/life_course_vacc_policy_report_interactive.pdf²⁰ https://www.sciencedirect.com/science/article/pii/S0264410X19312046?dgcid=coauthor

8. Acknowledgments

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²¹ http://ippez.pl/