

Latest Studies on Immunology

Chapter 1

Vaccination: The Pathway for a Concrete Citizens' Engagement

Mariano Votta^{1}; Daniela Quaggia²*

¹*Mariano Votta, Director Active Citizenship Network, c/o Cittadinanzattiva APS. Via Cereate, 6 - 00183 Rome (Italy).*

²*Daniela Quaggia, Deputy Director Active Citizenship Network, /o Cittadinanzattiva APS. Via Cereate, 6 - 00183 Rome (Italy).*

Email: m.votta@cittadinanzattiva.it & d.quaggia@activecitizenship.net

Abstract

Vaccine hesitancy – the reluctance or refusal to vaccinate despite the availability of vaccines – threatens to reverse progresses made in tackling vaccine-preventable diseases. For this reason, vaccine hesitancy has been identified by the World Health Organization (WHO) among the 10 many issues that will demand worldwide attention in the coming years. Mainly to address these and other threats, 2019 saw the start of the World Health Organization's new 5-year strategic plan – the 13th General Programme of Work [1]. Besides the commitment of the institutions and of the various stakeholders, the civil society needs to be mobilized. But how much impact does the lack of adequate health literacy have? What could the contribution of the civil society be in reducing vaccine hesitancy? How can we be able to involve citizens' organizations? Which characteristics should a message on vaccines have in order to be effective? In the present opinion article, we look at citizens' engagement on vaccination: from the analysis of a concrete experience promoted at the EU level by a citizen organization, step by step the pathway to increase the number of citizen organizations dealing with vaccine hesitancy across Europe and to improve the awareness on the importance of vaccination among EU citizens.

Keywords: Vaccine Hesitancy; Good Practices; Citizens' Engagement; EU; Civic Activism.

1. Introduction

Vaccination is a right and an extraordinary tool of public health, which must be known, valued, spread and used in the interests of individuals and the community. However, it is necessary to work and contribute to a proper vaccine culture. In addition, it is necessary to ensure rigor and transparency, in order to recover confidence in science.

Cittadinanzattiva - Active Citizenship Network (ACN) [2] is deeply committed to contribute to raising awareness about the importance of vaccination in Italy and across Europe [3]: immunization is vital to prevent diseases and protect life.

Its 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, Cittadinanzattiva feels a great responsibility to commit to this issue: it is believed that a widespread vaccination culture is necessary, particularly to overcome the idea that vaccination happens only when 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.



2. Materials and Methods

This opinion article aims to describe an experience carried out at the Eu level from January 2018 to January 2020 by Active Citizenship Network, the EU branch of the Italian NGO Cittadinanzattiva. Through a qualitative approach and a long-term strategy, focused on the following described four steps, it was possible to enlarge the constituency of the actors much involved and active on the topic of vaccination, and in particular on the long-life immunization approach.

Each step for a concrete **citizens' engagement on vaccination policies** is composed by title,

description, qualitative (categories involved) or quantitative data (numbers of initiatives), and summarized by a message and a picture, to be intended as material of the article.

3. Increasing Health Literacy on Vaccination

Education is one of the most important social determinants of health. Many past studies have shown strong relations between poor health literacy and disease. An adequate education on health would allow people to understand why vaccination is necessary. More in **general**, health literacy is an essential element for the achievement of satisfying results in the health sector. To compensate to a chronic lack of health literacy – of the basic knowledge in the health sector – wide partnerships that involve everyone are needed: from the governments to medical and scientific communities; from the private sector to media. The latter have a huge responsibility in influencing and shaping public opinion. For example, on the topic of vaccine hesitancy, a very interesting study produced in the framework of the European Joint Action on Vaccination (EU-JAV) and presented last 28th January 2020 at the EU Parliament, shows how relevant is the Identification of influencers, pro and anti-vaccine, on the main social media[4].

The protection of citizens' rights, not only patients, cannot be guaranteed without proper information, especially on the subject of vaccines where it is essential to distinguish reliable sources of information from fake news. It is believed that a well-informed citizen who is aware of his rights is a resource for the society. For this reason, it is crucial to invest in the empowerment of citizens.

In concrete, last 6th of November 2018, Active Citizenship Network organized in Brussels a European training seminar on the theme of life-course vaccination opened to 20 selected leaders of civic and patients associations coming from different countries (Belgium, Bulgaria, Hungary, Italy, Ireland, Spain, Slovenia, Slovakia, Albania, Kosovo, Croatia, Malta). The reason was to respond to the need to be more up-to-date and prepared in the face of a phenomenon (the decrease in vaccination coverage) that has returned to topical relevance; to better identify, recognize and fight against the increased external factors that can negatively influence the vaccine policy in EU Member States and have updated information & knowing how to recognize official sources of information.

As key experts, representative of the WHO Regional Office for Europe (Vaccines and their impact on public health), the EU Commission- DG SANTE (Overview European Vaccines Plan), the Federation of European Academies of Medicine (Distinguishing between credible source of information and fake news), the Italian Society of Pediatrics (vaccination diary for life).

For many associations, it was the first time to discuss for so high-level experts. A concrete example of partnership between civic society and the scientific society.

The message is: each one of us, when well-informed, represents a good antidote to the diffusion of fake news.

3.1. Promoting Institutional Dialogue for a Political Approach on Vaccination

The follow-up of the training session was characterized by their involvement in public events at the European Parliament, where the topic of vaccination was approached as a global and cross-border phenomenon, not circumscribed to an isolated context. A topic which also affects the sustainability of healthcare systems, as the lack of vaccination and the degree of vaccination coverage have a strong impact on public health expenditures.

This step was necessary for at least two reasons: a) to identify how to build a close collaboration and dialogue with European institutions and stakeholders across the health care spectrum to determine how we can work together to a more effective civic society engagement in vaccination policies. b) to discuss in a plural basis and to achieve a political goal: the Coalition for Vaccination, one of the 20 concrete actions included in the “Proposal for a Council Recommendation on Strengthened Cooperation against Vaccine Preventable Diseases” [5] has been extended for the first 2 meetings also to all the civil society’s representatives engaged on the topic, instead of being opened only to the European associations of healthcare workers and relevant students’ associations in the field, as written in the Council Recommendation of 7 December 2018 [6].

The message is: civic participation in healthcare policies should be considered not only as a praiseworthy civic act, but also as a strategic source to safeguard the public healthcare system.



4. Collecting Data and Producing Evidences

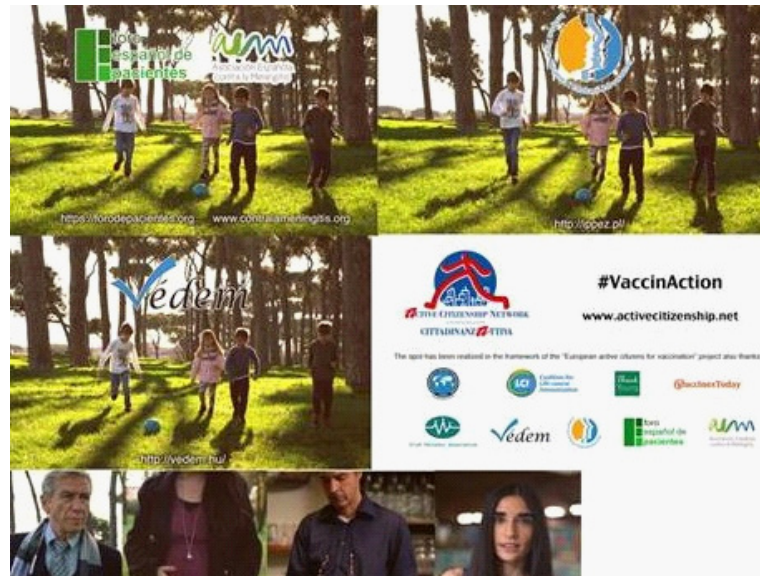
Immunization is vital to prevent diseases and protect life. Correct, but as we don't live in a perfect world, there are citizens who convey fake news about it. Luckily, there are also many socially responsible citizens, the most of us. In a context of widespread vaccine hesitancy, for example, active citizens can be producers of social information. Civic information touches everyday reality and does not concern only impressions. Making civic information means aggregating, creating networks and alliances, having a clear will to change things. Therefore,

the role of active citizens and groups that promote active citizenship is important.

For instance, in the framework of vaccination policies, with the cooperation of many partners at the national level (mainly Poland, Spain, and Hungary), at the end of 2019 Active Citizenship Network has realized in different EU Countries a civic consultation through focus groups on the specific theme of the life-course immunization approach in the national immunization plan, and so promoted a discussion on how is it organized and perceived in each country. Putting together around the table different key actors (leaders of civic and patients association, healthcare professionals, policy makers and other experts and possible stakeholders involved in the administration of vaccines), the aims of the activity was to find proposals together and gather impressions, suggestions, advices on that aspect and provide institutional and health care stakeholders with: the strengths/weaknesses of national policies and plans on life course - vaccination for each selected country; the common elements or specificities that affect a greater or lower success of this approach in the different countries. Results will be published within the 2020.



By doing all this, it is believed that a useful role is being played from at least two points of view: first, we produce civic information and data. Afterwards, we use this knowledge to do activities and to promote politics that connect interlocutors: not only citizens as such, but also social and economic actors that decide to take a common path, because they consider possible that things can be changed. We are convinced that civic networks can play a great role as they are in contact with the people and their reality. For this reason, the role of civil and active society is to connect institutions and communities: in times of vaccine hesitancy, **the message is: where institutional communication does not arrive, civil society arrives.**



4.1. From citizens to citizens for a more reliable communication

In 2017 our claim was “Be active on vaccines!”. The same concept has been reinforced along 2018 “Active Citizens in Europe advocate for vaccination” and 2019 “European active citizens for vaccination”. The concept has been summarized with #VaccinAction which accompanies the 2020 social media communication campaign. It has been co-created with the direct involvement of associations and experts, most of them already engaged in the previous initiatives above described. The campaign is the contribution of Cittadinanzattiva-Active Citizenship Network to strengthen the message linked to the annual European Immunization Week, and it took into consideration the relations between social media and fake news [7]. Following the suggestion of the experts from Bambino Gesù Children’s Hospital IRCCS, Rome (Italy), while continuing to provide evidence on the efficacy and safety of vaccines, it was decided to adopt for the communication campaign a reframing of vaccine communication that focuses on the positive, emotional values of immunizations [8].

It is a short spot with flash interviews of citizens who talk about the topic of vaccines, providing positive data taken from official sources. It sends a unified, clear and strong message on the importance of vaccination directly from citizens to citizens; leaders and activists engaged in social, civic and patients associations, parents, teachers, health workers, bloggers and popularizers: everyone can commit to disseminate correct scientific information, ready to defend the importance of vaccination from the wave of misinformation that is being spreading for some years. The social media campaign is spread throughout Europe and in several languages (Italian, Polish, Hungarian, English and Spanish), with videos produced, shared and customized for each country involved. Moreover, an informative leaflet in a different language has been produced [9].

The message is: “Together, as active and aware citizens, we can protect ourselves: become the champion of your future!”.

5. Results

To increase health literacy on vaccination; to promote institutional dialogue for a political approach on vaccination; to collect data and produce qualitative recommendations; to involve citizens as the champion for a more efficient communication aimed at citizens themselves: at least these four steps are needed to emphasize the decisive role of the civil society, of the citizens' organizations and the advocacy groups in this challenging and complex environment. We believe the involvement of the civil society actors in the discussions on vaccination is crucial. The commitment for vaccination can only be effective if the message reaches citizens, if the tools are available for all of us as well as the correct information. It is strongly believed that there is a clear added value to strengthening cooperation among all relevant actors at the EU level, including health authorities, the vaccine industry, research and innovation, the healthcare sector and others. However, the involvement of the civil society has to be first guaranteed, also to address the WHO Europe Vision of an "European region free of vaccine-preventable diseases, where all countries provide equitable access to high quality, safe, affordable vaccines and immunization services throughout the life course"[10].

The message is: The only way to overcome the considerable challenges that vaccination programs are facing is to be more active on vaccines!



6. Discussion and Conclusion

In many European countries, civic participation represents since always a strategic element in the National Health Service, and a pivotal point for international actions and strategies. Despite this, barriers which prevent citizens from bringing contributions to the different phases that compose the cycle of public policies still exist. In the last years, several processes for the involvement of citizens began to make their own way, but there is still a long way to go for citizens' participation in health policies to become active and effective.

Exactly from the viewpoint of the overcoming of these barriers and of the strengthening of citizens' empowerment can be seen the multi-annual commitment of Active Citizen Network on an European level, which, starting from the main threats to health, wants to contribute to the overcoming of these obstacles, with the general objective of a greater empowerment and civic

involvement in the health sector, with particular reference to vaccination policies.

Taking into consideration certain rigidities, which limit European debate to Brussels only, and the objective effort of European Institutions to involve the largest number of actors, the pan-European experience above described testifies the effort but also the utility to transfer the recent achievements, messages and commitments on the topic of vaccination from the European to the national level.

The message is: vaccination has to be intended as a citizen right for the whole population.

7. Ethic Statement

The authors have worked in full compliance with the Code of Conduct of Cittadinanzattiva APS[11].

Written in March 2020, it means in the era of the corona virus pandemic, the authors have decided to avoid in this article any connection between the global pandemic and vaccination, even if they are confident that the experience of pandemic will teach us at least the following lessons: from one hand, that no one global health issue can be managed by the Institution without the engagement of the civic society as a whole and the correct behavior of the citizens is a key. From the another hand, that the anti-vax approach and the skepticism about vaccination are absolutely a non-sense. The request to discover a vaccine against the corona virus pandemic is the common hope all around the world.

8. Conflict of Interest and Funding

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9. Acknowledgements

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10. References

1. WHO, "Ten threats to global health in 2019": <https://bit.ly/2wjwIqu>
2. Cittadinanzattiva APS has more than 40 years of experience in protecting citizens' rights in the health sector. Starting from 2001, through its EU branch, Active Citizenship Network (ACN), Cittadinanzattiva has been promoting civic participation and rights' protection, also at European level, gathering almost 200 civic and patients' organizations all over the Continent. Over the years, it has been increasing Cittadinanzattiva - Active Citizenship Network contributions for the promotion and protection of citizens' rights in the fields of vaccination. <https://bit.ly/2QD1EJb> and <https://bit.ly/2vGarmn>

3. “The Engagement of Cittadinanzattiva on Vaccination”: <https://bit.ly/2xZwFR5>
4. “Platform for real-time monitoring of data on conversations on vaccines on the web and social media” by Bambino Gesù Children’s Hospital IRCCS, Rome (Italy): <https://bit.ly/33C1Cq4>
5. Proposal for a Council Recommendation on Strengthened Cooperation against Vaccine Preventable Diseases COM/2018/244 final - 2018/0115, published by the EU Commission on 26.4.2018 and included in the Council Recommendation of 7 December 2018: <https://bit.ly/2uOcV1w>
6. Official Journal of the European Union, Council Recommendation of 7 December 2018 on strengthened cooperation against vaccine-preventable diseases (2018/C 466/01): <https://bit.ly/2wiFkwZ>.
7. Health Economics 2019 Nov; 28(11):1377-138 “Vaccine hesitancy and (fake) news: Quasi-experimental evidence from Italy”, by Carrieri V, Madio L, Principe F. <https://bit.ly/2Wyjwss>. Human Vaccines and Immunotherapeutics 2018 Jul 3;14(7):1654-1659 “Misinformation on vaccination: A quantitative analysis of YouTube videos”, by Donzelli G, Palomba G, Federigi I, Aquino F, Cioni L, Verani M, Carducci A, Lopalco P. <https://bit.ly/33BTvd6>
8. Vaccine 36 (2018) 5107–5108: “To talk better about vaccines, we should talk less about vaccines”, by Francesco Gesualdo, Nicola Zamperini, Alberto E. Tozzi from Bambino Gesù Children’s Hospital IRCCS, Rome, Italy. <https://bit.ly/2UuqbRC>
9. All the materials are available on the webpage: “European active citizens for vaccination – 2019”: <https://bit.ly/39a5fVB>
10. “European Vaccine Action Plan 2015-2020”: <https://bit.ly/2xbtK7o>
11. Cittadinanzattiva APS, “Codice di Condotta”: <https://bit.ly/3brghr5>