



Contents lists available at ScienceDirect

## Vaccine

journal homepage: [www.elsevier.com/locate/vaccine](http://www.elsevier.com/locate/vaccine)



### Review

## Civil society: A critical new advocate for vaccination in Europe

Vanina Laurent-Ledru<sup>a</sup>, Angus Thomson<sup>b,\*</sup>, Joseph Monsonego<sup>c</sup>

<sup>a</sup> MSD, Paris, France

<sup>b</sup> sanofi pasteur, Lyon, France

<sup>c</sup> Women Against Cervical Cancer, Geneva, Switzerland

### ARTICLE INFO

#### Article history:

Received 25 May 2010

Received in revised form 12 October 2010

Accepted 1 November 2010

Available online xxx

#### Keywords:

Human papillomavirus

Vaccination

Civil society

Immunization policy

### ABSTRACT

The vaccinology landscape has changed, with national authorities now being increasingly accountable to new stakeholders such as health insurers, regional regulatory bodies, the media, and civil society. Here, we discuss how civil society organisations (CSOs), such as patient and women’s groups, have become important drivers in the introduction and sustainability of new vaccination programs. This shift in public implication in vaccine policy has been well illustrated in the recent introduction of human papillomavirus (HPV) vaccination in Europe. Patient and women’s groups which were traditionally focused on advocacy of treatments have also become advocates for prevention with the advent of HPV vaccination. Civil society advocacy at the European level supported key resolutions and white papers which in turn informed national recommendations on cervical cancer vaccination. CSOs were also active at the national level, supporting national policy makers. These organisations may bring innovative and effective new approaches to communication on vaccination benefits, using public events, celebrities and various social media. Working with experts, CSOs can also be an important bridge from the science to the lay public. This may provide a vital counterbalance to media hype and antivaccination groups, although CSOs may also be active and vocal opponents of immunization. The successful implementation and sustainability of future vaccination programs against infections such as HIV will be dependent upon the active participation of civil society to inform, to reassure and to maintain public trust.

© 2010 Elsevier Ltd. All rights reserved.

### Contents

1. Introduction.....	00
2. Stakeholder empowerment has changed the vaccinology landscape.....	00
3. Civil society groups as drivers of vaccination programs .....	00
3.1. HPV vaccination in Europe .....	00
3.2. Paving the way for implementation of an HIV vaccine .....	00
4. Civil society as a barrier to vaccination.....	00
5. The future of civil society advocacy in vaccinology .....	00
6. Conclusions .....	00
Conflict of interest statement.....	00
References .....	00

### 1. Introduction

The long-term success of a new vaccination program is dependent upon the sustained commitment and implication of diverse stakeholders. Traditionally this primarily includes policymakers and others involved in the regulatory processes. However, the

introduction of HPV vaccination into Europe has illustrated the importance of new actors, such as scientific societies, medical and scientific experts, the ECDC, health insurers and civil society organizations (CSOs) such as cancer leagues, women’s associations and patient groups, in the successful implementation of a vaccination program [1].

Civil society may be defined as the part of society that consists of organizations that look after people, their health and their rights. It does not include the government or the family [2]. The importance of this social arena, “in which people engage in activities with public consequence”, to all aspects of health, from grassroots to global

\* Corresponding author at: sanofi pasteur, Global Immunisation Policy, 2 Avenue Pont Pasteur, 69367 Lyon, France. Tel.: +33 4 3766 9686; fax: +33 4 3737 7202.

E-mail address: [angus.thomson@sanofipasteur.com](mailto:angus.thomson@sanofipasteur.com) (A. Thomson).

health policy, is being increasingly well recognized [3]. Here, we argue that in vaccinology, a cornerstone of public health, civil society is rapidly assuming its rightful place as a driver of change and public confidence.

**2. Stakeholder empowerment has changed the vaccinology landscape**

Traditionally, vaccinology was driven by national regulators, who called upon experts and the vaccine industry to provide clinical and safety data and other expertise during decision making leading to implementation of national vaccination programmes. This evolved in the 1990s as regulators became increasingly accountable to new stakeholders such as health economists, regional regulatory bodies, the media, and civil society (Fig. 1). These stakeholders are becoming increasingly empowered and demanding more of a voice in vaccine decision making.

Patients are at the centre of two important recent trends in healthcare which have led to the specific empowerment of civil society. There has been an evolution in healthcare away from a “disease-centred” approach toward a “patient-centred” approach. With a disease-centred approach, doctors make most treatment decisions based on clinical experience and the evidence-base, in a process in which the patient remains passive. In the patient-centred model which is increasingly implemented alongside the traditional approach, patients take an active role in their own care. In addition, the public have increasing access to medical information, primarily online, which is leading to a healthcare ‘reformation’ [4], in which easily accessible information is shifting power from the medical profession to the laity. Together, these two interrelated trends have led to the increasing empowerment of the public, and consequently increasing recognition of the need for the public voice to be heard in healthcare policy. This latter point is well illustrated by the inclusion of civil society representatives in the EMEA Roadmap to 2015, which states: “An element of growing importance is the involvement and participation of civil society representatives (patients/users of medicines and healthcare professionals) in the Agency’s activities” [5]. This shift in public implication in vaccine policy has been well illustrated in the recent introduction of human papillomavirus (HPV) vaccination.

**3. Civil society groups as drivers of vaccination programs**

**3.1. HPV vaccination in Europe**

HPV vaccines represent a major advance in the prevention of cervical cancer and other HPV-related diseases. The availability of both HPV vaccination and cervical cancer screening creates the unique opportunity to combine primary and secondary prevention for a cancer. Originally only involved in advocacy of treatments, with the advent of HPV vaccination, patient and women’s groups for the first time became advocates of vaccination.

For example, working at the European level, the European Cancer Patient’s Coalition (ECPC) established a forum for members of the European Parliament (MEPs) called MEPs Against Cancer (MAC). The European Cervical Cancer Association also developed a network of politicians (called Politicians Against Cervical Cancer) who supported integration of HPV vaccination into cancer prevention programs. The ongoing advocacy of these two groups supported the eventual adoption of the European Parliament resolution on “Combating Cancer in the European Union” which called to “reinforce actions in favour of vaccination against cervical cancer”. Along with a subsequent request for “specific policies to be developed for cervical cancer” in the “White Paper: Together for Health: A Strategic Approach for the EU 2008–2013”, these documents provided important support for national recommendations on cervical cancer vaccination. The European Council also issued conclusions on reducing the burden of cancer, and stated that “the development of prophylactic vaccines against some carcinogenic viruses has opened up a new area in cancer prevention”. A number of other groups have also actively monitored progress on the issue, and this contributed to support the EU efforts related to cervical cancer, including the European Public Health Alliance (EPHA).

CSOs were also active at the national level, providing a base of support for national policy makers. In addition to patient groups such as Jo’s Trust in the UK, the promise of HPV vaccination also recruited, for the first time, women’s groups to vaccination [6]. O.N.Da. Advocacy campaigns such as that driven by 1000 Femmes 1000 Vies which posted advertisements in the Parisian metro, and O.N.Da, which complemented a large press campaign on cervi-

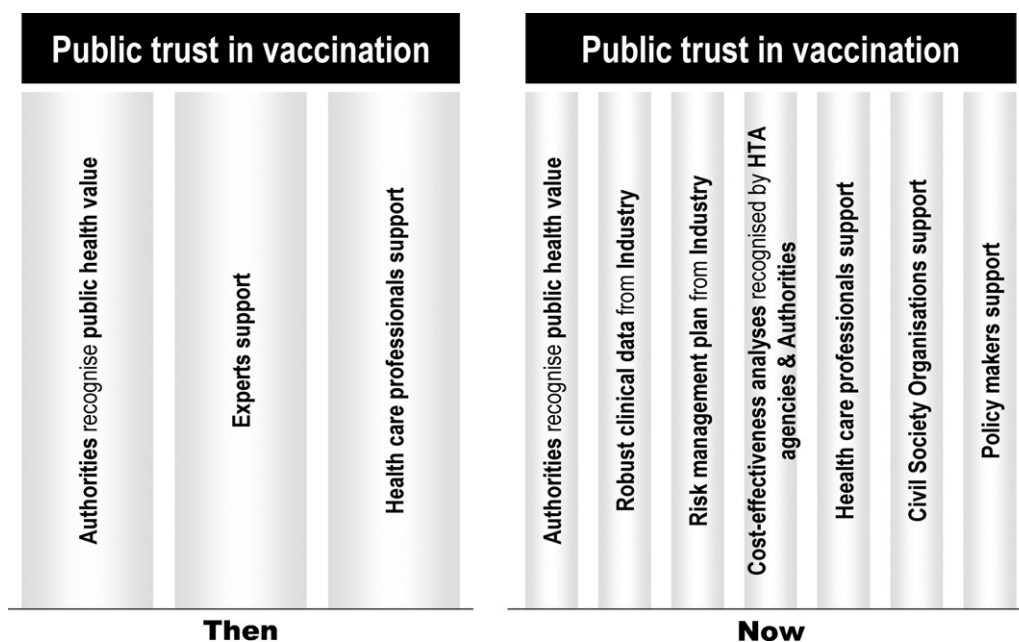


Fig. 1. The pillars of public trust and support for vaccination programs.

cal cancer prevention with distribution of leaflets on the metro, were an important means of building and sustaining public confidence in HPV vaccination programs [7,8]. These organisations often bring innovative and effective new approaches to communication on vaccination benefits, hosting large public events such as races against cancer, enlisting celebrities and using the many newer channels of social media to give a broader reach to the public. For example, engaging and informative videos can be viewed on the websites of the Association of Gynaecological Cancer Patients in Norway (Gynkreftforeningen) and Women against Cervical Cancer in Estonia (Naised Emakakaelavähi Vastu). A quick search of Facebook identifies numerous groups set up in memory to Jane Goody, the British celebrity who died of cervical cancer, many of which advocate HPV prevention. Gynkreftforeningen is also very active on Facebook, with almost 20,000 fans.

These CSOs have common missions: support for patients, raising awareness of authorities, and provision of reliable information. Thus, groups such as Women Against Cervical Cancer (WACC) (see Box ) often work in close cooperation with medical experts [9]. This

**Box 1: Women against cervical cancer: communicating expertise with empathy**

The WACC network [9] links about 50 CSOs in 20 countries. WACC was created and continues to be guided by medical experts in cervical cancer. These experts went beyond the traditional scientific circles to share their medical knowledge through CSOs who work in direct contact with the public. The organisation's five missions are: to inform, to gather, to educate, to work together and to take action. Through their website and regular meetings WACC provides standardised, accurate information on cervical cancer prevention in formats that can be readily adapted by the local member organisations. These tools include books, educational flyers, and videos in multiple languages, along with the provision of expert speakers for local events. Importantly, the information exchange is two-way; WACC conducts regular surveys through its member organisations on, for example, public knowledge and perceptions of vaccination [16], which inform future communication strategies. Meetings also provide a dynamic interface between women and patients and leading experts on cervical cancer and HPV.

provides a strong synergism; involvement of healthcare professionals ensures the scientific integrity of communications to the public, and encourages more active implication of physicians – a key driver of willingness to be vaccinated – in the success of vaccination programs. Furthermore, CSOs may help healthcare professionals better understand the patient perspective on vaccines and the various diseases they prevent.

Interestingly, the importance of civil society's role had already been well acknowledged by the research community, as evidenced by the many studies on patient and parental acceptance of HPV vaccination both before and after implementation [10–14]. While a number of these studies identified a high acceptance of HPV vaccination (from 75 to 86% among mothers and adolescents), there may be a gap between intention and actual vaccination [15]. CSOs can and should shoulder some of the responsibility for provision of accurate information on vaccine safety and benefits that might help close such a gap.

### 3.2. Paving the way for implementation of an HIV vaccine

The experience with implementation of HPV vaccination provides an unprecedented opportunity for civil society groups to inform future initiatives for the introduction of an AIDS vaccine; a process which will likely face similar challenges [17].

There are a number of common issues that may be foreseen with an HIV vaccine primarily related to the fact that the target population may be the same as that for HPV: adolescent girls.

Many recent studies have attempted to identify the challenges related to the possible stigma of a vaccine for adolescents against a sexually transmitted infection. Even before HPV vaccination became available, the acceptability of the vaccines among teenagers and parents had been widely studied [11,13,18], the ethics of possible vaccination policies analysed [19], the optimal means of delivery to early adolescents and sexually active young women debated [20], and strategies for the integration of vaccination with existing prevention programs advocated [21,22]. After the roll-out of HPV vaccination programs, studies again evaluated acceptance of vaccination [14] and the results of efforts to educate and build acceptance amongst the public [23].

Such studies tacitly acknowledge the importance of public perception, and inform practical initiatives to ensure that public trust is gained and maintained. It is in this arena that CSOs provided key support, building public awareness of the medical needs and public health benefits of HPV vaccination with a non-condescending voice that did not come from the authorities or experts, which carried a perceived credibility that endorsed the scientific evidence.

## 4. Civil society as a barrier to vaccination

Although the majority of parents believe that vaccines effectively protect their children from disease, concerns about vaccine safety can reduce their willingness to vaccinate, and the available information that addresses these concerns often fails to reach and convince parents [24]. The MMR vaccine and autism controversy continued for over a decade despite a large body of scientific evidence discounting the link [25], and scientific discreditation of the single flawed study that triggered the loss of public confidence. Why does good science often fail to maintain public confidence in vaccination? Research suggests that if communication of scientific evidence, no matter how solid, is not tempered by a more human, empathetic element, the reader will be less engaged, and actually feel less informed [26]. Science, the product of rational thinking, fails to satisfy the fundamental human motives to understand self and our environment, to have a sense of control over events, and to find the world benevolent. Experimental thinking, which draws largely upon anecdotal evidence and emotional response, satisfies these motives by establishing a causal attribution based on personal experience, and is thus the more common approach taken by the lay public towards understanding health [27].

In this context, small groups that oppose vaccination have achieved a disproportionate voice in public discussions on vaccination. These groups are often quoted in the media to provide “balance” to a story in which all the scientific experts may be aligned in favor of a vaccine [28–30]. In the Netherlands, for example, a slower-than-expected start to HPV vaccine uptake was attributed to misinformation distributed by groups such as the Dutch Association for Critical Vaccinations opposed to vaccination on the internet and at vaccination centers, leading government public health experts to actively and publically counter the claims [31,32]. Examples of other such groups include JABS in the UK and the French Ligue Nationale Pour la Liberté des Vaccinations [33,34]. Indeed, these voices do provide a balance to the scientific evidence, however inappropriate and inaccurate, by providing an experiential interpretation, emotive and rich in anecdote, which serves to reassure and satisfy the public.

Speers astutely noted that “the battle for public trust . . . can no longer be won by straightforward appeals to authority: it needs to be based on an understanding of the nature of public concern” [28]. The more active engagement of health professionals in communication of the benefits of vaccination to the public is essential [35]. But CSOs are also well positioned to help close the gap between the head and the heart in the public perception of vaccination. Their humanizing input to remind people, for example, of the known risks of not vaccinating will be vital to sustaining public trust in vaccination programs.

## 5. The future of civil society advocacy in vaccinology

Civil society will therefore play an increasingly important role in both facilitating the introduction of new vaccines and ensuring the sustainability of ongoing vaccination programs. CSOs must continue to provide an informed and reassuring voice to gain and maintain public confidence, and to engage authorities and remind them of the public interest in vaccination programs.

The availability of an effective HIV vaccine will only be the first step towards control of the disease. The HPV example illustrates the many challenges of a new vaccination program in adolescents, but also confirms the importance of the committed implication of CSOs to adoption of vaccination and long-term success of a program. There are promising candidate vaccines against two important nosocomial pathogens, *Staphylococcus aureus* and *Clostridium difficile*. Healthcare-associated infections are already on the agendas of patient groups such as Health First Europe and the European Patient Forum, a member of the European Commission’s Patient Safety Working Group [36,37]. The engagement of such organizations at both the local and European level will be an important buttress to any new vaccination program targeting nosocomial infections. Cancer patient groups are already very interested in experimental therapeutic cancer vaccines; indeed one group even sued the FDA over a delay in the approval of a prostate cancer vaccine. Somewhat less extreme advocacy from these well organized and motivated groups may help moderate patient expectations as these new therapies become available, and provide support for recommendations, funding, and acceptance by physicians of these new modalities of therapy.

## 6. Conclusions

Outbreaks of measles, mumps and rubella in Europe and the US are recent reminders of the innate fragility of any immunization program. In the evolving environment of vaccinology, there is increasing awareness that it is only through the concerted and active efforts of all stakeholders, including policymakers, scientists, and crucially civil society, that the sustainable success of vaccination programs can be guaranteed. This is because political will and public acceptance are crucial new determinants, in addition to the science and public health policies, of the success of vaccination program. CSOs are thus increasingly becoming a potential driver of public confidence in vaccination, by tempering the science communicated by experts and authorities with an empathy that increases the receptivity of the public audience. However, this approach may also be used to oppose vaccination by these organizations. Either way, CSOs now represent an important reference on public vaccination perceptions and needs for authorities. In public health, at the important level of vaccination, civil society is already assuming its rightful place as a driver of public trust.

## Conflict of interest statement

VLL is the President of a women’s association called univers’Elles. AT is employed by sanofi pasteur, and VLL is employed by MSD; both companies make vaccines. JM is the President of Women Against Cervical Cancer, and has consulted for manufacturers of HPV vaccines.

## References

- [1] Van Damme P, Pecorelli S, Joura EA. The introduction of policies for human papillomavirus vaccination in Europe. *J Public Health* 2008;16:291–8.
- [2] Macmillan dictionary; 2010. Available from: <http://www.macmillandictionary.com/dictionary/american/civil-society> (accessed May 2010).
- [3] Loewenson R. Overview of issues from the bibliography on civil society and health. Available from: <http://www.tarsc.org/WHOCsl/overview.php> (accessed March 2010).
- [4] Shaw J. A reformation for our times. *BMJ* 2009;338:b1080.
- [5] EMEA. The European Medicines Agency Road Map to 2015 EMA/299895/2009. Available from: <http://www.emea.europa.eu/pdfs/general/direct/directory/29989509en.pdf> (accessed May 2010).
- [6] Jo’s Trust. Homepage available at: <http://www.jotrust.co.uk> (accessed May 2010).
- [7] 1000 Femmes, 1000 vies. Homepage available at: <http://www.1000femmes1000vies.org/> (accessed May 2010).
- [8] O.N.Da (Osservatorio Nazionale sulla salute della Donna). Homepage available at: <http://www.ondaosservatorio.it/inglese/index.html> (accessed May 2010).
- [9] Women Against Cervical Cancer network. Homepage available at: <http://www.wacc-network.org> (accessed May 2010).
- [10] Marlow LA, Waller J, Wardle J. Parental attitudes to pre-pubertal HPV vaccination. *Vaccine* 2007;25:1945–52.
- [11] Woodhall SC, Lehtinen M, Verho T, Huhtala H, Hokkanen M, Kosunen E. Anticipated acceptance of HPV vaccination at the baseline of implementation: a survey of parental and adolescent knowledge and attitudes in Finland. *J Adol Health* 2007;40:466–9.
- [12] Kahn JA, Rosenthal SL, Jin Y, Huang B, Namakydoust A, Zimet GD. Rates of human papillomavirus vaccination, attitudes about vaccination, and human papillomavirus prevalence in young women. *Obstet Gynecol* 2008;111:1103–10.
- [13] McClelland A, Liamputtong P. Knowledge and acceptance of human papillomavirus vaccination: perspectives of young Australians living in Melbourne, Australia. *Sex Health* 2006;3:95–101.
- [14] Brabin L, Roberts SA, Stretch R, Baxter D, Elton P, Kitchener H, McCann R. A survey of adolescent experiences of human papillomavirus vaccination in the Manchester study. *Brit J Cancer* 2009;101:1502–4.
- [15] Mortensen GL. Drivers and barriers to acceptance of human papillomavirus vaccination among young women. A qualitative and quantitative study. *BMC Public Health* 2010;10:68.
- [16] Women Against Cervical Cancer network. WACC Report 2008; European Disease Awareness Barometer. Available from: [http://www.wacc-network.org/survey/wacc\\_report\\_2008.pdf](http://www.wacc-network.org/survey/wacc_report_2008.pdf) (accessed May 2010).
- [17] RHO Cervical Cancer. Current HPV vaccines and future AIDS vaccines: common challenges and unprecedented opportunities; 2008. Available from: <http://www.rho.org/vaccination.htm> (accessed May 2010).
- [18] Davis K, Dickman ED, Ferris D, Dias JK. Human papillomavirus vaccine acceptability among parents of 10- to 15-year-old adolescents. *J Low Genit Tract Dis* 2004;8:188–94.
- [19] Zimmerman RK. Ethical analysis of HPV vaccine policy options. *Vaccine* 2006;24:4812–20.
- [20] Wright TC, Van Damme P, Schmitt H-J, Meheus A. HPV introduction in industrialized countries. *Vaccine* 2006;24S3:S3/122–/10.
- [21] Raffle AE. Challenges of implementing human papillomavirus (HPV) vaccination policy. *BMJ* 2007;335:375–7.
- [22] Bosch FX, Castellsaguè X, de Sanjosè S. HPV and cervical cancer: screening or vaccination? *Br J Cancer* 2008;98:15–21.
- [23] Shefer A, Markowitz L, Deeks S, Tam T, Irwin K, Garland SM, Schuchat A. Early experience with human papillomavirus vaccine introduction in the United States, Canada and Australia. *Vaccine* 2008;26(Suppl. 10):K68–75.
- [24] Freed GL, Clark SJ, Butchart AT, Singer DC, Davis MM. Parental safety concerns in 2009. *Pediatrics* 2010;125:654–9.
- [25] Elliman D, Bedford H. MMR: where are we now? *Arch Dis Child* 2007;92:1055–7.
- [26] Hargreaves I, Lewis J, Speers T. Towards a better map: science, the public and the media. ESRC Available from: <http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/Mapdocfinal.tcm6-5505.pdf> (accessed May 2010).
- [27] Lindeman M. Motivation, cognition and pseudoscience. *Scand J Psychol* 1998;39:257–65.
- [28] Lewis J, Speers T. Misleading media reporting? The MMR story. *Nat Rev* 2003;3:913–8.
- [29] Gordon, B. Cervarix: the simple injection causing so much controversy. *The Telegraph* 2009. Available from: [http://www.telegraph.co.uk/health/women\\_shealth/4986930/Cervarix-the-simple-injection-causing-so-much-controversy.html](http://www.telegraph.co.uk/health/women_shealth/4986930/Cervarix-the-simple-injection-causing-so-much-controversy.html) (accessed May 2010).

- [30] Poland GA, Spier R, Editorial. Fear, misinformation and innumerates: how the Wakefield paper, the press, and advocacy groups damaged the public health. *Vaccine* 2010;28:2361–2.
- [31] Nederlandse Vereniging Kritisch Prikken. Homepage. Available at: <http://www.nvkp.nl> (accessed September 2010).
- [32] Sheldon T. Dutch public health experts refute claims that human papillomavirus vaccination has health risks. *BMJ* 2009;338:b1109.
- [33] JABS. Homepage. Available at: <http://www.jabs.org.uk> (accessed September 2010).
- [34] Ligue Nationale Pour la Liberte des Vaccinations. Homepage. Available at: <http://www.infovaccin.fr> (accessed September 2010).
- [35] Bedford HE, autism: MMR. Health professionals must enter the public arena if future debacles are to be prevented. *BMJ* 2010;340:c655.
- [36] Health First Europe. Homepage. Available at: <http://www.healthfirsteurope.org/> (accessed May 2010).
- [37] European Patients' Forum. Homepage. Available at: <http://www.eu-patient.eu/> (accessed May 2010).