



Engaging the cancer community for cervical cancer elimination

Landscape of civil society engagement in HPV vaccination

Summary of findings

October 2023



“Civil society organisations play a very robust role in the elimination of cervical cancer including through the vaccination target of covering 90% of girls by 2030. In this regard, we work on community awareness including with the media, we can also work on health facility awareness, and also be involved in advocacy activities with the government to give special attention to this programme. It is one of the major cancers impacting the country and the second leading burden. We need more attention, more financing, and more resources for these interventions.”

CSO, Ethiopia

Executive summary

Cancer civil society organisations (CSO) play a critical role in advancing access to and uptake of HPV vaccination primarily through advocacy, awareness raising and community mobilisation, and all in the broader context of addressing cervical cancer across the life course and continuum of care. Whilst there is substantial diversity in terms of cancer CSOs and contextual determinants of their engagement in advancing HPV vaccination, there are a number of common success factors, needs and challenges experienced across settings:

- Cancer CSOs report similar challenges to increasing uptake of HPV vaccination, specifically regarding stigma, lack of information and misinformation in populations
- As trusted voices, experts in local needs, influencers and mobilisation drivers, CSOs serve as an fundamental complement to national HPV programmes
- CSOs show agility, adapting to their ecosystems and bridging gaps in engaging with populations and communities
- CSOs report the lack of resources to sustainably engage, and the need to build a track record and reinforce organisational capacities before benefitting from local and global grant-making opportunities to sustainably implement activities
- In order amplify CSOs' impact in HPV vaccination, a clear value is seen in the opportunities for peer-to-peer learning on communication materials and strategies that are adaptable for local implementation of programmes.

Background

Primarily caused by high-risk infection of the human papillomavirus (HPV), cervical cancer is the fourth most prevalent cancer in women worldwide and claims a life every two minutes. 90% of all cases and deaths due to cervical cancer occur in low- and middle-income countries (LMICs). As part of its focus on women's cancers, the Union for International Cancer Control (UICC) is committed to the implementation of the [Global Strategy for the elimination of cervical cancer](#), in particular in supporting the engagement of the cancer community across the 90-70-90 targets to be achieved by 2030.

Since 2022, there seems to have been a particular and renewed momentum for accelerating access to primary prevention through HPV vaccination programmes, where coverage still stands at a lower level than the target with only 55% mean coverage in LMICs¹. This momentum builds on global commitments, such as Gavi's ambition to vaccinate 86 million girls by 2025, as well as country-level progress with 20 additional countries having introduced the vaccine in 2022/23, totalling 136 countries worldwide. Issued in December 2022, the one-dose recommendation of the [WHO Strategic Advisory Group of Experts on Immunization \(SAGE\)](#) also represents a significant opportunity for further scale-up of access in many settings. This momentum has also translated into the emergence of alliances and coalitions worldwide to advance cervical cancer elimination.

UICC is committed in supporting cancer civil society organisations (CSO) to continue to be key enablers in the implementation of the cervical cancer elimination agenda, as part of wider cancer prevention and control. In order to further leverage this specific momentum on HPV vaccination, UICC conducted a landscaping of its community to understand and explore ways to support cancer CSOs in their engagement in the introduction and scale-up of HPV vaccination in their context. As part of this landscaping exercise, UICC sought to answer the following questions:

- What are the specific contributions that cancer CSOs can make to improve access and uptake of HPV vaccination in their own settings?
- What are CSOs' perceptions of strengths, barriers and facilitators in the engagement in HPV vaccination?
- How do CSOs and stakeholders formulate the key needs for support in order to advance HPV vaccination as part of cervical cancer elimination?

1. WHO/UNICEF Estimates of National Immunization Coverage (WUENIC), 2023.
<https://www.who.int/news/item/18-07-2023-childhood-immunization-begins-recovery-after-covid-19-backslide>

Methodology

The study was conducted from June to September 2023, based on a mixed-methods approach, combining a rapid scoping review of the literature and national policies, a quantitative survey as well as qualitative interviews, case studies and focus group discussions.

The uniqueness of this landscaping exercise lies in its focus on the voice of UICC members, specifically cancer CSOs from LMICs, across three main regions.

Quantitative survey: 109 responses across 67 countries

Drawing from a sample of approximately 200 UICC members, representing CSOs engaging in women’s cancers in LMICs, a quantitative survey was conducted to assess engagement and key activities.



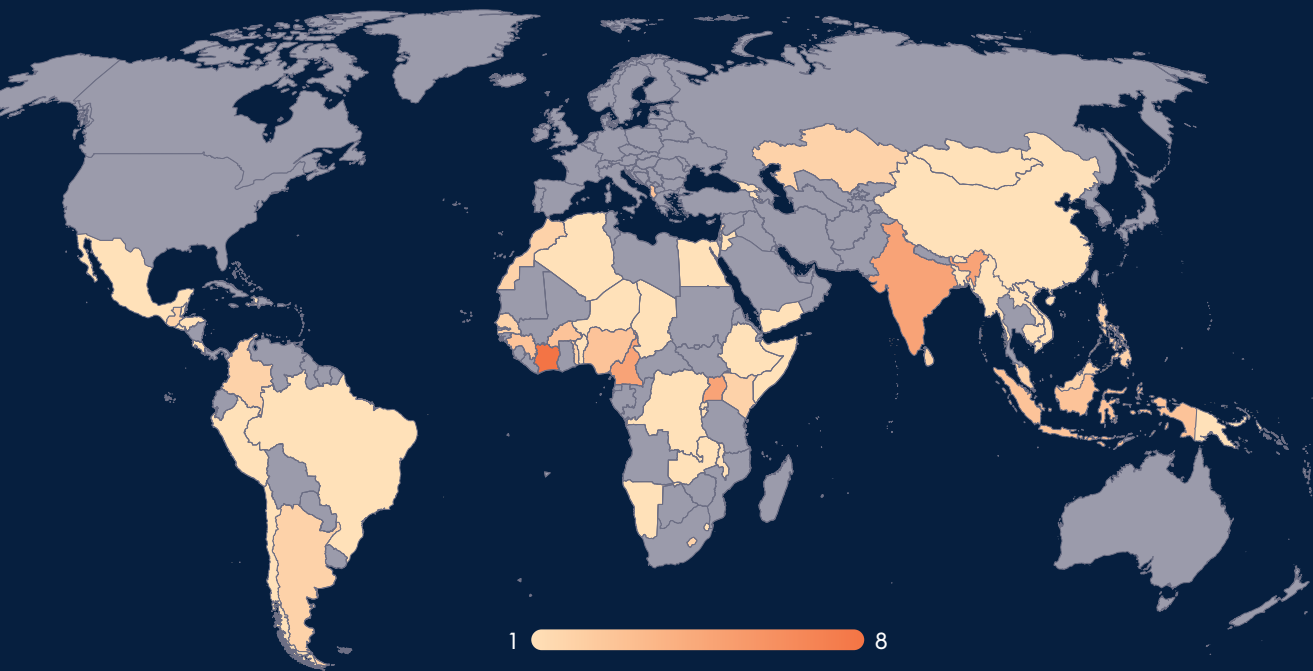
Regional representation of respondents:

Africa:	48%
Asia-Pacific:	23%
Eastern Mediterranean:	9%
Europe:	6%
Latin America:	14%

This regional representation is proportional to UICC’s membership in the regions, except for a higher engagement from the African region.



Geographic representation of survey respondents



Methodology

Qualitative interviews: 50 interviews in 37 countries

A purposive sampling approach was taken and sought to ensure the diversity of perspectives, geographically and in terms of the type of UICC members (cancer societies, patient groups, civil society coalitions), with 40 key informant interviews conducted with individuals from cancer CSOs from 37 countries in LMICs. Through a further 10 interviews, UICC's membership was also leveraged to include perspectives from key stakeholders (technical, financial partners, cancer programmes, national cancer institutes, international NGOs) working with CSOs. Nine case studies were developed to illustrate examples of CSOs' specific roles and types of engagement in terms of HPV vaccination. Finally, as a last step, to verify and test the findings, two online focus group discussions were conducted in English and French with CSOs (38 participants in total) to ensure a feedback loop on preliminary findings.



Key findings

The landscaping offered a unique opportunity to understand and explore the role of the cancer community as a core stakeholder in advancing HPV vaccination, as part of their broader engagement with women, girls and their families for cervical cancer elimination. In presenting the findings, the report will provide highlights from the quantitative survey, with further contextual insights in each area drawing from the key informant interviews.

Overall perception of CSOs on access to and uptake of the HPV vaccine

An important prerequisite for engagement of CSOs is the perception of availability of the vaccine in the respective contexts. While 82% of respondents reported some availability of the vaccine, further insights highlighted substantial supply and demand-side barriers that in fact limit access and achievement of the 90% target of girls to be vaccinated.

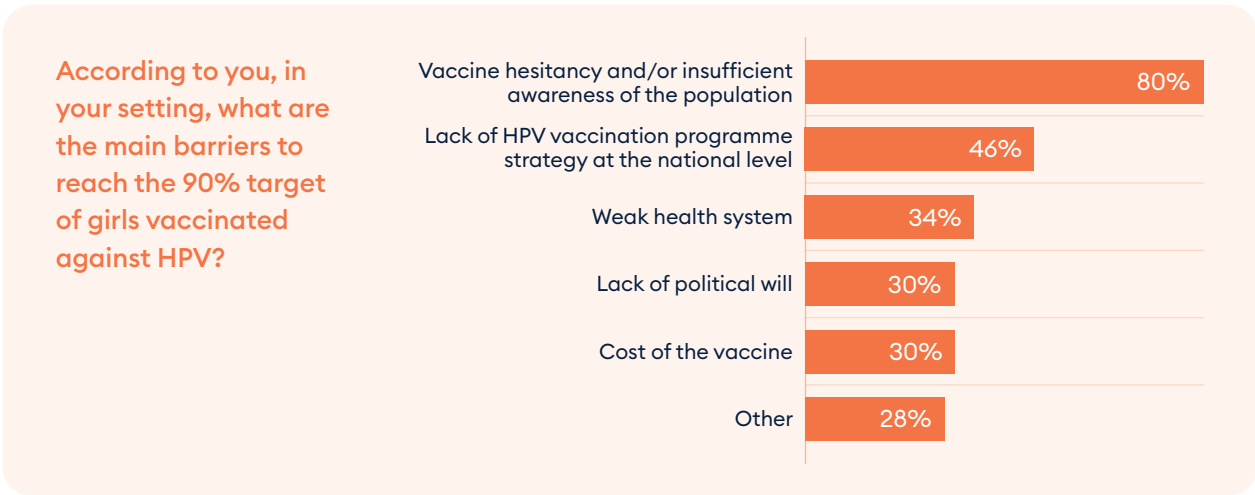
The lack of information and vaccine hesitancy were highlighted as the main barrier to reaching the 90% target, with the omnipresence of stigma being seen as a clear limitation on the uptake of vaccination.

The lack of affordability was perceived as one of the key barriers depending on contexts. Informants also stressed issues with national programmes failing to resume after interruptions due to the Covid-19 pandemic or to scale-up due to budgetary difficulties and/or the lack of readiness of health systems. The lack of reliable data was also mentioned as a key barrier in informing programmes.



“This is all about the 2 A’s: Awareness and Affordability. Once you get those two blocks and there is access, then there is no reasons why it should not move”

CSO, Philippines



Key findings

Level of engagement of cancer CSOs

Overall, 66% of survey respondents reported some level or type of engagement in terms of the introduction or scale-up of HPV vaccination. Of the remaining respondents, 23% were not currently engaging but were willing to, and 11% reported that they were not engaging.

The main reasons for lack of engagement were the lack of funding (50%), other competing priorities in the organisation (28%) and the lack of knowledge as to how to engage in the area (22%). Other reasons were primarily linked to the lack of access to the vaccine.

Through the key informant interviews, a number of individuals shed further light on reasons for not engaging, for example, in low income settings, the lack of availability or affordability of the vaccine played a key role in the level of engagement. The understanding and positioning of CSOs' role in health systems can also be an important variable regarding the level of engagement.



"It varies from one country to another, for us, this is mainly the government, and there are complementarity of roles. As an NGO, our role is primarily around accompaniment of patients during their care."

CSO, Rwanda

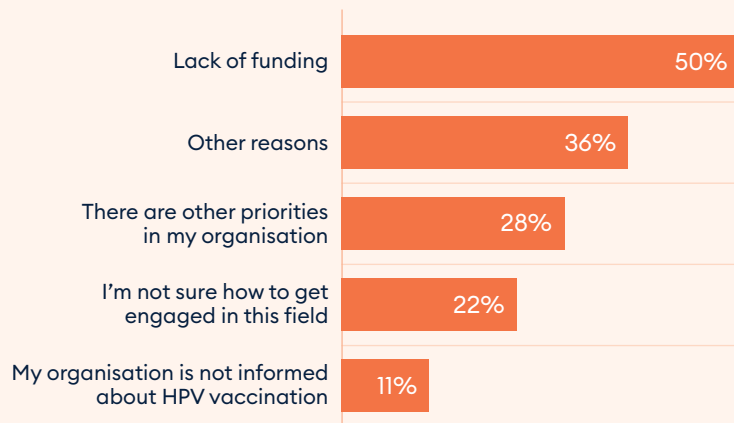
Where cancer CSOs are engaging in HPV vaccination, it is important to acknowledge that they do so as part of a broader engagement and commitment to cervical cancer elimination. All qualitative inputs highlighted that the cancer CSOs engaged in all three targets, in primary and secondary prevention as well as support to patients of cervical cancer, through a patient-centred approach.



"What I really appreciate regarding the role of CSOs, it is their effort to link vaccination to secondary prevention. This is a key role in integrating the various programmes for cervical cancer elimination."

Global stakeholder

Reasons for not engaging in HPV vaccination



Beyond diversity: sharing the voice of communities

Cancer CSOs are diverse, from the grassroots survivor group to broader coalitions. However, despite this diversity, they share similar perceptions of strengths. CSOs play an “important role in both facilitating the introduction of new vaccines and ensuring the sustainability of ongoing vaccination programs”². Particularly, CSOs are drivers of social mobilisation and community engagement, which has been recognised as a key success factor for high coverage of HPV programmes in LMICs. From this perspective, two recurrent themes across all data are trust and first-hand experience as major strengths of cancer CSOs in the communities. As highlighted by one of the stakeholders:



“Why CSOs? Because CSOs really bring that local experience, they understand the community better than anyone else, they engage in communities and are the trusted voices in communities. I think our work is stronger because CSOs have been engaged throughout the programme.”

Global stakeholder

CSOs also appear to be neutral brokers across all stakeholders, putting the community at the centre, for engagement, mobilisation as well as accountability.



“CSOs actively engage, in every opportunity, with all stakeholders to identify gaps and work with them to eliminate those gaps such as financial and cultural barriers.”

Survey respondent

More specifically, cancer CSOs perceive their role as complementary to the one of local or national public authorities, through close collaboration to support the introduction and/or roll-out of vaccination programmes, particularly for geographically or culturally hard-to-reach communities. Close collaboration and planning hand-in-hand with the government were highlighted as a key enablers for successful and sustainable impact.



“The organisation supported the government develop the roll out of the HPV vaccine with community engagement and messaging. The government relies on CSOs to break down barriers in reaching communities.”

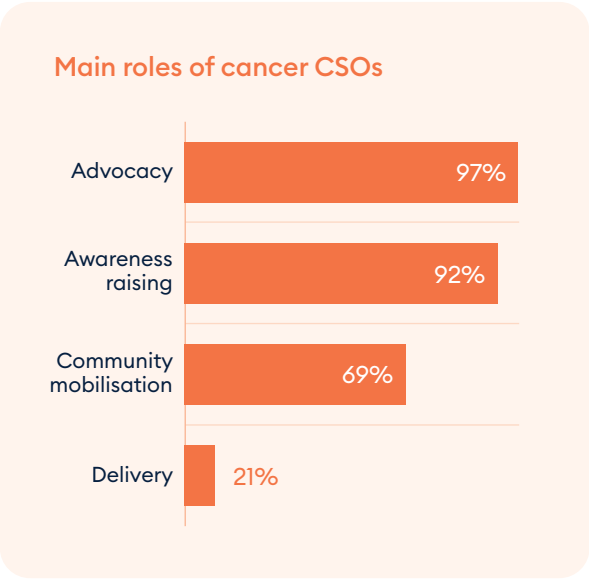
CSO, Samoa

2. Laurent-Ledru V, Thomson A, Monsonogo J. Civil society: a critical new advocate for vaccination in Europe. *Vaccine*. 2011 Jan 17;29(4):624-8.



Matrix of cancer CSOs’ roles in HPV vaccination

Building on these strengths, cancer CSOs engage in HPV vaccination through various roles as part of their activities on cervical cancer elimination.



Key findings

Engaging through evidence-based advocacy

According to the survey, about 97% of organisations engaging in HPV vaccination were involved in advocacy efforts. They position themselves as drivers of change on policies as well as through direct participation in decision-making³.

As part of their advocacy tools, participating CSOs mentioned:

Influence - engaging champions in the government or parliament as well as in advocacy. In Indonesia, a civil society coalition engaged with parliamentarians as well as celebrities to advocate for the introduction of HPV vaccination.

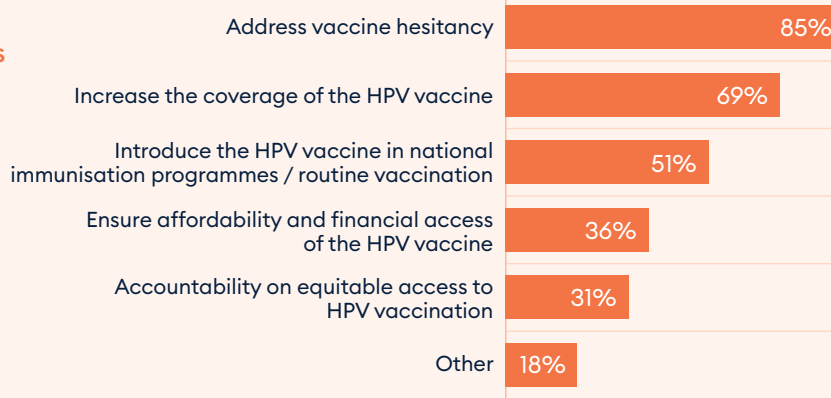
Creating evidence - making the case for roll-out and paving the way for successful implementation of vaccine programmes. Cancer CSOs collaborate with academia to conduct studies on acceptability and act as data drivers in their context. In Nigeria, a CSO led a pilot study to generate evidence on contextual factors, including girls knowledge and perceptions, to inform subsequent roll-out of the programme in schools.

Policy dialogues - participating in national consultations, technical working groups and decision-making bodies. In Guatemala, the technical working group on cervical cancer elimination is led by a cancer CSO engaging in substantial advocacy efforts towards a law on HPV vaccination.

Oversight - ensuring that national budgets align with commitments, reporting on implementation and impact of HPV programmes in communities to hold governments accountable. In the Philippines, a cancer coalition monitors implementation of HPV vaccination and engages annually in budget advocacy to ensure adequate financing of commitments towards cervical cancer elimination.

Leveraging these advocacy tools, key focus areas of advocacy efforts are as follows:

Main priorities of advocacy activities



3. International Vaccine Access Center (IVAC), Understanding Priorities and Needs for HPV Vaccine Advocacy: Findings from a Global Survey, IVAC at the Johns Hopkins Bloomberg School of Public Health, Baltimore, May 2023.

Key findings

Raising awareness through appropriate narrative

As public acceptance is a crucial determinant of reaching the 90% target for HPV vaccination, and given vaccine hesitancy, cancer CSOs engage substantially in raising awareness through information campaigns, with 92% of respondents reporting engagement in this area.

As the trusted voice with populations, CSOs are key drivers of public confidence. Those CSOs who reported engaging in awareness raising for HPV vaccination, had the following focus areas, as indicated in the graph below.

Participants emphasise specifically the lack of information, myths and stigma as a factor of inequity. They also report major stigma regarding the HPV vaccine from a gender perspective, notably the myths around fertility as well as sexually transmitted diseases.



“The communication deficit is a factor of inequity. We need to address the obstacle of fear and stigma. When people know, they want to vaccinate their children.”

CSO, Morocco

From the cancer community perspective, CSOs alternatively adopt narratives on the prevention of cancers associated with HPV, including cervical cancer, and on positive messaging with girls and their parents.

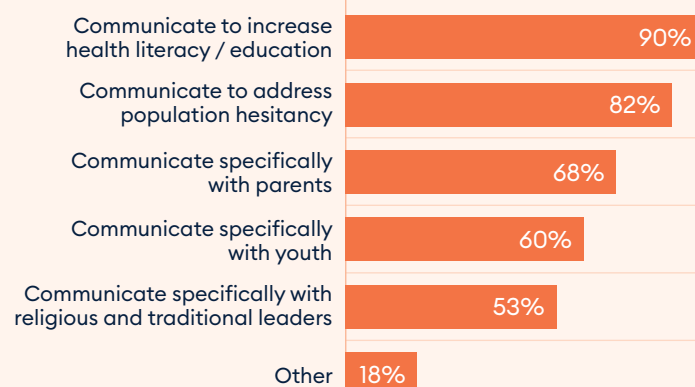


“We need to reframe the messaging positively. We need to emphasise that it’s not only against cervical cancer but also other cancers as well. This is really a cancer vaccine.”

CSO, Philippines

The main channels of communication used are in-person mobilisation (87%) and social media (87%) and engagement with press and media (81%), leveraging global awareness events such as Pink October or World Cancer Day. Working with influencers is perceived as the most impactful strategies for public information.

Main priorities of awareness raising activities



Key findings

Mobilising communities through targeted approaches

More specifically, in the context of demand generation, cancer CSOs play a significant role (78% of respondents) in supporting the implementation of HPV vaccination programmes through increasing knowledge and engagement of specific communities in local settings. Capitalising on their reputation as trusted voices and their in-depth experience in working with communities, CSOs engage with various stakeholders such as health professionals, schools as well as traditional and religious leaders, who are key influencers in communities.

CSOs collaborate with health workers, general practitioners, nurses, midwives, community health workers as well as pharmacists as critical points of contact for populations.

Targeted approaches with schools and traditional leaders are perceived as essential in the delivery of the HPV vaccination.

Complementary approaches with authorities: CSOs are working in close collaboration with local authorities and can also be involved with the review and adjustment of information, education and communication (IEC) materials to achieve the best impact and adherence in communities.



“We don’t create parallel activities in the country. We piggyback on what already exists and we capitalise on resources that are there and bridge gaps. So, when we leave, we leave a sustainable programme that can continue working.”

CSO, Kenya

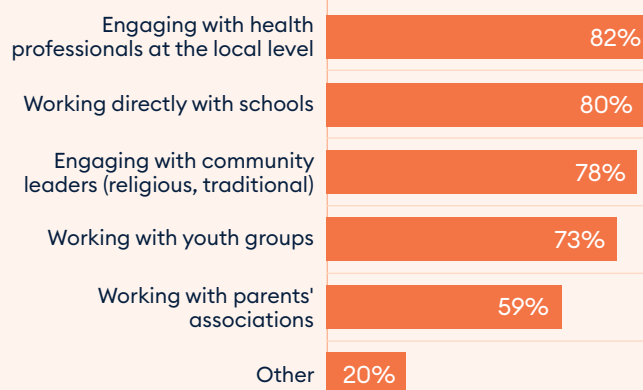
Integrated approaches: From the cancer community perspective, integrated approaches are inherently implemented in their community mobilisation activities – either as part of cervical cancer elimination, or more broadly as part of women’s cancers. For example, CSOs in Cameroon and Senegal implement mother-daughter programmes addressing primary and secondary prevention jointly, and the training of health workers integrates all aspects of cervical cancer elimination.



“We leveraged a research project on secondary prevention of cervical cancer to integrate activities of demand creation for vaccination, with community discussions in the health districts. We insisted to include these activities in the project with the funders.”

CSO, Senegal

Main priorities of community mobilisation activities



Key findings

Leading delivery for specific populations

Only 21% of survey respondents mentioned direct delivery of the vaccine as part of their activities in HPV vaccination. These activities were related to specific contextual aspects, such as:

- Specific delegation to CSOs for delivery in hard-to-reach communities
- Dedicated programme for childhood cancer survivors
- Donation programmes implemented directly in communities, or for catch-up strategies in addition to national programmes.



Key barriers in deploying activities

CSOs reported facing several external and internal obstacles in sustainably engaging in HPV vaccination across their various activities as part of cervical cancer elimination.



External obstacles:

Conflicts and economic crises resulting in shifting priorities for the CSOs

Lack of availability and affordability of the HPV vaccine

Stigma and misinformation of populations

Lack of data for advocacy, planning activities and assessing impact

Lack of political will and/or engagement of authorities to collaborate with and amplify CSOs activities

Circumvention of local CSOs by external partners in the implementation of programmes in communities

For delivery, limited and/temporary supply, cost of the vaccine, important programmatic costs for the delivery of the vaccine



Internal obstacles:

Insufficient resources (funding as well as human resources) for implementing activities

Earmarked funding and donors mandates not aligned with needs in communities (rural areas)

Lack of expertise and confidence in sharing information (e.g. justification for single dose)

Insufficient awareness of global opportunities (e.g. Gavi CSOs opportunities, eligibility)

Limited organisational skills (grant writing, fundraising, track record)

Opportunities to amplify CSOs' impact in HPV vaccination

Based on the extensive engagement of CSOs in driving change in their settings for HPV vaccination and cervical cancer elimination, the value of exchanging experiences was perceived as one of the main opportunities to support and reinforce sustainable engagement of CSOs for HPV vaccination.



Key wins in advocacy

Sharing key levers for successful engagement and impact as well as strategies for oversight



Examples: mapping of stakeholders driven by CSOs, engagement of champions, oversight strategies



Engagement in research

Sharing protocols and strategies to become data drivers & engage in collaboration with academia



Examples: KAP study, pilot project in a district, formative evaluation on acceptability



Implementing integrated approaches

Sharing steps for successful integration (awareness, demand creation)



Examples: Mother-daughter programme, joint awareness campaigns



Informing HPV messaging

Sharing materials and innovative strategies to be adapted to local contexts



Examples: IEC materials, social media tags, adaptable messaging



Reported needs for support

Participants mentioned several key needs for learning and support:

Knowledge for advocacy

Information, training and peer-learning on:

- Basics of vaccinology, incl. single dose
- How to advocate for health financing
- How to harness data for advocacy and community mobilisation
- How to leverage global opportunities

Communication for public education

Materials and training on:

- Adaptable standardised materials
- How to design communication strategies
- Training of trainers approaches for journalists

Grants and technical assistance on:

- Design and impact assessment of activities (e.g. Project ECHO)
- Implementation of activities (initiation or scale-up)
- Tools for specific audiences (health professionals, youth, leaders)

Organisational skills for sustainability

Training and tools on:

- Mapping of stakeholders, coalition-building
- Implementation research
- Grant writing and management
- Building sustainable partnerships

Overview of results

- ✓ **66% of cancer civil society organisations in UICC's community engage in HPV vaccination**, alongside and in the context of other activities to address cervical cancer across the life course and continuum of care.
- ✓ **97% engage in advocacy** for HPV vaccination, **92% in awareness raising** and **69% in community mobilisation**. Only 21% engage directly in HPV vaccine delivery.
- ✓ CSOs' main strengths are **trust and in-depth knowledge** of communities' needs.
- ✓ Main external barriers are **access to the vaccine, stigma, insufficient data and fragmentation of stakeholders**.
- ✓ Main internal barriers are **insufficient human and financial resources, siloed approaches** by stakeholders, need to reinforce **organisational skills and awareness of opportunities**.
- ✓ Key highlighted opportunities for amplification of CSOs' impact in HPV vaccination include **peer-to-peer learning, grant-making** as well as **access to learning and technical support for communications, advocacy and implementation**.





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