

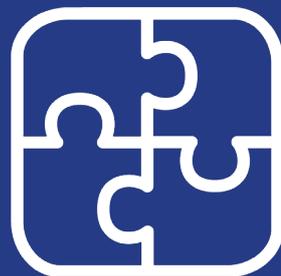


HPV
PROTECT
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Choose vaccination. Get tested. Prevent cancers.

Making a Difference: Advocating for HPV Policy Change

A PRACTICAL GUIDE



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Abbreviations

ECO - European Cancer Organisation

EPF - European Parliamentary Forum for Sexual and Reproductive Rights

ESGO - European Society of Gynaecological Oncology

HPV - Human papillomavirus

IARC - International Agency for Research on Cancer

IPVS - International Papillomavirus Society

NCD - Non-communicable disease

NITAG - National Immunisation Technical Advisory Group

WHO - World Health Organization



Foreword



Prof. Csaba Dégi, President, European Cancer Organisation

In the past few years HPV has become one of the most significant issues in European cancer policy. Effective vaccination and screening programmes now offer the possibility of preventing tens of thousands of cancer cases caused by HPV, in men and women, all across Europe each year. In many countries, however, progress is too slow and too many lives are being lost unnecessarily.

Advocacy can help to put that right. Organisations and individuals can work together to put effective pressure on decision-makers, cut through the inertia, and create the cancer prevention services of the type and scale that are urgently needed across the region. We have already seen the impact of effective advocacy campaigns on HPV policy in several countries and Europe-wide.

This guide is based on the experience of many of them. It distils the lessons learned into eight essential ingredients for advocacy success. We hope it will be useful not only to the campaigns highlighted in this guide as they continue their invaluable work but also to others engaged, or who might yet be engaged, on this issue.

The prize is certainly worth advocating for: the elimination of an entire type of cancers and a huge sum of human suffering.

Executive Summary

- HPV is a major cause of cancer in Europe and around the world. It is directly responsible for around 5% of all cancers in men and women worldwide.
- These cancers can be easily prevented by vaccination. Cervical cancer screening can also detect pre-cancers so they can be treated before cancer develops.
- HPV has in recent years become one of the most significant issues in European cancer policy. But too many countries are still not doing enough to tackle HPV. Out of 47 countries across the European region, just five are performing well on key indicators related to vaccination, screening and online public information.
- Advocacy can play a crucial role in persuading and pushing governments and Ministries of Health to do better. Civil society organisations can help to ensure that the right policies are introduced and implemented.
- ECO invited organisations and individuals that have been involved in advocacy to a special symposium to share their experiences and to identify the essential ingredients of effective advocacy on HPV policy.
- Eight essential ingredients were identified:
 1. Identify the problem, including the extent of HPV-related diseases in men and women.
 2. Recruit partners. There is strength in numbers and the more support a campaign has the more effective it is likely to be.
 3. Get the governance right. Partners need to be involved in the development of the campaign's terms of reference including how decisions are made. A written constitution should be agreed and kept under review.
 4. Decide on goals and objectives. These should be clear, broad, potentially achievable and few in number. They must also be agreed by the partners.
 5. Analyse the policy landscape to help develop and frame policy goals and to develop the campaign strategy. It is easier to achieve goals that are at least partly aligned with the direction of national policy.
 6. Develop a strategy and a budget. Campaigns should identify the resources available and decide how they can be most effectively utilised.
 7. Take action. An action plan should set out what will be done, by who and when. The outcomes of any activity should also be recorded.
 8. Monitor and evaluate progress and outcomes.
- There have now been several very effective campaigns on HPV policy in Europe. Decision-makers can be persuaded to make the right decisions on vaccination, screening and public information. Advocacy can really work and result in less suffering and more lives saved from the devastating cancers caused by HPV.

Introduction

HPV is a major cause of cancer in Europe and around the world. It is directly responsible for around 5% of cancers worldwide.¹ Cervical, vaginal, vulval, anal, penile and oropharyngeal cancers are among those caused by HPV. Women are most at risk, mainly from cervical cancer, but up to 40% of HPV cancers are in men.² In Europe, an estimated 90,000 cancer cases are caused by HPV each year. HPV also causes genital warts and RRP (recurrent respiratory papillomatosis), a rare but potentially disabling condition that affects breathing.

At any one time, 22% of men in Europe have a high-risk (oncogenic) HPV infection;³ the equivalent figure for women is about 4% rising to about 21% in Eastern Europe.⁴ Most of those infected will not develop cancer – their immune systems will tackle the infection effectively – but, unfortunately, too many will.

HPV infection has recently been linked to some other cancers – including prostate, breast and lung cancers – and also to cardiovascular disease. However, further research on HPV's relationship (if any) with these diseases is needed before it can with confidence be cited as a causative factor.

HPV cancers can be easily prevented by vaccination. Just one injection is enough, ideally delivered to all young people before sexual 'debut'. Cervical cancer screening is also essential to detect pre-cancers so they can be treated before cancer develops.

Too many countries are not doing enough on HPV. Europe's Beating Cancer Plan wants to see gender-neutral HPV vaccination across all Member States by 2030 with a 90+% uptake in girls and 'significantly greater uptake in boys. (ECO believes there should be an explicit 90% target for everyone.) The Plan also wants Member States to ensure that 90% of the population who qualify for cervical cancer screening are offered it by 2025.

However, the EPF/ECO HPV Policy Prevention Atlas shows that, out of 47 countries across the European region, just five (all in North-West Europe) are performing well on key indicators related to vaccination, screening and online public information.⁵ 17% of countries do not offer an HPV vaccination programme at all, however, and 36% do not offer gender-neutral vaccination.

Governments and Ministries of Health often need to be persuaded and pushed into doing better. Scientific data, however credible, is on its own not always enough to bring about a change in policy. And that is where advocacy can make the difference. Civil society organisations have an opportunity to play a vital role in ensuring that the right policies are introduced and implemented.

This report provides guidance about how to advocate effectively on HPV and draws on the experience of organisations that have done this – and in many cases are still doing this – in Europe and beyond.

To help prepare this guide, ECO invited organisations and individuals that have been involved in advocacy to share their experiences and to identify the essential ingredients of effective advocacy. The participants, whose organisations are listed in the Appendix, also had an opportunity to comment on a draft of this guide.

ECO will use the guide to inform its own advocacy work and the work of its member and partner organisations. We also hope it will be of use to any organisation, whether in Europe or beyond, that wishes to advocate on HPV policy to save lives and reduce suffering.

WHAT IS ADVOCACY?

"Advocacy is about seeking systems change, it is how civil society can influence the adoption (or strengthening) of policies, programmes, regulations, legislation and even funding allocations. It requires following a thorough and well-thought approach to promote and defend a specific issue, based on a clear understanding of the surrounding social, public health, political and policy context, building support of key constituencies to influence key decision-makers in taking a specific action to achieve a desired change. Advocacy is not a one-off event or activity, but a strategic process following a plan designed to achieve a desired change."

NCD Alliance. Practical Guide to Strategic Advocacy Planning (2022).⁶

The Eight Essential Ingredients of Effective HPV Policy Advocacy

1. Identify the problem
2. Recruit partners
3. Get the governance right
4. Decide on objectives and goals
5. Analyse the policy landscape
6. Develop a strategy and a budget
7. Take action
8. Monitor and evaluate

1. Identify the problem

A good place to start is to identify the extent of HPV disease in your country. The WHO focuses on cervical cancer alone, but ECO recommends a wider perspective that takes account of all the cancers caused by HPV – cervical, vaginal, vulval, penile, anal and some head and neck cancers (particularly oropharyngeal cancer). It is now feasible, through vaccination and screening, to eliminate all the cancers caused by HPV and a strong case can therefore be made for action beyond cervical cancer.

To compile data, make use of your country's published cancer statistics. The International Agency for Research on Cancer (IARC) publishes national incidence, mortality and prevalence data for 36 cancer types across 185 countries.⁷ In Europe, ECO's European Cancer Pulse provides information about cancer incidence and mortality, and data about HPV vaccination and cervical cancer screening, for countries across the WHO European region.⁸

One important issue is to assess what proportion (known technically as the 'attributable fraction') of each relevant cancer is caused by HPV.⁹ This can vary from country-to-country and region-to-region but there is broad agreement that almost all (99.9%) of cervical cancers are caused by HPV as are around 90% of anal cancers and over 50% of penile cancers. For oropharyngeal cancers, however, the estimates vary from about 30% to over 70%. 52% has been suggested as the attributable fraction for

oropharyngeal cancer in the United Kingdom, for example. While it is tempting for advocacy purposes to build a case based on a higher estimate, it is important to ensure that the figure chosen is credible for the country concerned.

The proportion of HPV cancer cases affecting men as well as women also needs to be identified. Again, this will vary between countries and regions but credible estimates range from 20–40%. There is also robust recent evidence suggesting that 21% of men globally are carrying a high-risk (oncogenic) HPV infection at any time and are therefore a risk to anyone unvaccinated they have sexual contact with.

Key questions include:

On cancer rates

- What are the incidence and mortality rates for all the cancers caused by HPV in both men and women?
- How do these rates compare to neighbouring or similar countries and to Europe (or your region outside of Europe) as a whole?

On HPV vaccination

- Is HPV vaccination free and easily available, especially to young people?
- Is vaccination available to all genders?

- What is the level of vaccination uptake?
- What are the barriers to vaccination?
- Do any population groups and/or geographic areas have significantly lower levels of vaccination uptake?

On cervical cancer screening

- Is cervical cancer screening available nationally as part of an organised programme?
- How often is screening offered?
- Does the screening programme use HPV testing?
- Is self-sampling available as an option in the screening programme?
- What is the level of screening uptake?
- What are the barriers to screening?
- Do any population groups and/or geographic areas have significantly lower levels of screening uptake?

You might also want to look at whether easy-to-use evidence-based information about vaccination and screening is available online in your country for use by young people and their parents/carers as well by those eligible for cervical cancer screening.

The EPF/ECO HPV Prevention Policy Atlas provides useful information on 47 European countries but, because the data was collected before June 2023, it may need to be checked for accuracy.

2. Recruit partners

There is clearly strength in numbers. Generally speaking, the more support a campaign has, the more effective it is likely to be. The fact that many organisations and individuals share the same goal adds credibility in the eyes of decision-makers and, not only can the campaign speak on behalf of all the partners, they can also use their influence and networks independently to make the case.

HPV affects several cancer sites so there could be organisations and individuals that focus on one or several of these who could be interested as might those who have a broader involvement in cancer, oral health, sexual health, women's or men's health, or public health generally. Recruiting clinical or

IDENTIFY THE PROBLEM – CASE STUDY

When ECO's HPV Action Network decided that its advocacy work would focus not only on the European Commission and WHO Europe but also on individual countries, it needed to know which countries were falling behind in terms of HPV vaccination and cervical cancer screening. ECO commissioned the Catalan Institute of Oncology, a world-leading research organisation that collects and analyses data of vaccination and screening for the WHO, to produce a report which looked at the policies of countries across the region. This evidence formed the basis of ECO's decision to focus its advocacy work on Romania, Bulgaria and Croatia in the first instance.

scientific organisations, or individual clinicians and scientists, will also help to add credibility.

When considering who to invite to be part of the campaign, it is also worth thinking 'outside of the box'. Youth organisations, for example, trade unions, sports bodies, are also potential partners, often with considerable influence over politicians and policymakers.

There may be commercial organisations who would like to get involved. This could be helpful in terms of profile-raising as well as financially but beware of any potential conflicts of interest or how decision-makers and others might perceive a partnership. If a commercial partner would benefit financially – in terms of product sales, for example – this could create the very damaging impression that the campaign is effectively the company's mouthpiece.

Key questions include:

- Which organisations and individuals would add value to the campaign as partners?
- What is the best way to recruit them?
- How many partners can be effectively managed and co-ordinated?
- Do any of the partners come with 'baggage' or create potential conflicts of interest that could undermine the campaign's credibility?

RECRUIT PARTNERS – CASE STUDIES

HPV Action UK recruited over 50 partners to its campaign for gender-neutral HPV vaccination. These were a mix of patient and professional organisations (large and small, national and local) and came from a wide range of backgrounds including cancer, public health, sexual health, men's health, gay men's health, oral health and women's health. Student and trade unions also signed up.

The **HPV Coalition** in Bulgaria, **Hellenic Alliance against HPV** (Greece) and the **HPV Coalition** (Croatia) and **HPV Action Romania** have adopted a similar model and all have multiple partners fully engaged in their campaigns. ECO's **HPV-Hep B Action Network** also has over 50 organisations as members and stakeholders. These include a significant number of young people's organisations.

3. Get the governance right

Partners and others involved in the campaign need to be comfortable with how decisions are made and how any problems will be dealt with. They will want to be sure that their name or brand is associated with an organisation they can trust and which will not reflect badly on them. This means that attention must be paid to getting the governance right.

The governance of the campaign is a matter for its members to decide collectively. Normally, a constitution or governing document will be agreed by the founding organisations and kept under annual review. Embodying commitments to democracy, transparency, accountability and inclusivity, the document will state the organisation's aims and objectives, how partners are appointed, how the leadership is selected and held to account, and how partners are kept informed of developments and can participate in decision-making.

The campaign may wish to hold quarterly or six-monthly general meetings which are open to all members and appoint a small executive committee which will meet monthly with the campaign leadership and report back to the general meetings.

The document should set out the goals of the campaign, the roles and responsibilities of all

members (including any financial commitments) as well as the executive committee and the campaign leadership. It should state how financial matters will be managed, such as where and how any funds will be held and transacted and how any fees or expenses will be paid. The document should address how any disputes between partners will be resolved and, should it become necessary, how any partner can be made to leave.

The legal identity of the campaign will depend on the laws of the country in which it is set up and will also need to be agreed and described in the governing document. Often, campaigns will wish to be no more than informal associations which have a light legal footprint and not be formally registered as companies or not-for-profits.

While drawing up a governing document may not seem like a priority and may even feel like an unnecessary distraction, not doing so may cause problems and cost much more time and effort in the long run.

Key questions include:

- What will be the legal identity of the campaign?
- How will decisions be made by the campaign?
- What will be the roles and responsibilities of the campaign's partners and any executive committee or leadership?
- How will the leadership be held accountable?
- How will a governing document be developed, agreed and implemented?

GET THE GOVERNANCE RIGHT – CASE STUDY

HPV Action Croatia has invested considerable time and effort in governance issues. At an early stage in its development, it established a steering committee from among the key campaign stakeholders, defined the roles, responsibilities and reporting structures, and at the inaugural meeting focused on identifying the strategic direction and specific objectives.

4. Decide on goals and objectives

Before its launch, the campaign will need to decide its key goals and objectives. These should be agreed by the founding partners and be set out in the governing document. The goals and objectives can be amended later, if the partners agree, but it would normally make sense to stick to the core calls to action.

To ensure maximum buy-in from potential partners, consider developing goals and objectives that are clear, broad, potentially achievable and few in number. Targets that are complex, very specific, and numerous or controversial are more likely to cause disagreements between partners. They are also more likely to be difficult to explain to other potential supporters and even policymakers and decision-makers.

Campaigns may wish to follow the acronym 'SMART' when it comes to deciding on goals and objectives. In other words, they should be:

- **Specific:** Targeting a particular issue for improvement.
- **Measurable:** Establishing indicators of progress and success.
- **Achievable:** The goals and objectives are attainable.
- **Realistic:** There are the necessary resources, commitment, skills, etc .
- **Time-related:** There is a timescale with milestones.

Key questions include:

- What are the campaign's goals and objectives?
- Are they 'SMART'?
- Have they been agreed all the campaign's founding partners and signed up to by subsequent partners?

5. Analyse the policy landscape

When deciding the goals and objectives and also the campaign strategy, it is important to take account of the policy landscape. In other words, what policies relevant to your campaign are currently being discussed and debated and are therefore more amenable to change.

DECIDE ON GOALS AND OBJECTIVES - CASE STUDIES

The **Hellenic Alliance against HPV** created the first Greek Declaration Against HPV which had three principal objectives: the vaccination of all girls; the inclusion of boys in the national vaccination programme; and the development and implementation of a national cervical cancer screening programme.

PASYKAF initially focused on creating greater awareness in Cyprus about the prevention of HPV-related cancers and achieving the establishment of a national school-based HPV vaccination programme for girls and later to extend this to boys. Once a gender-neutral vaccination programme had been achieved, the goals were amended to include a vaccination uptake target of 90% in girls and a significant increase in the uptake rate in boys.

In Italy, **Fondazione Veronesi** in collaboration with five other organizations developed a Manifesto on HPV which was signed and supported by other entities. The Manifesto called for improved access to vaccination and screening services, information campaigns targeted at young people, adults and clinicians, catch-up programmes for unvaccinated young people and unscreened women, and the monitoring of uptake through a digital registry. This document has been presented to the most relevant Italian national and regional political institutions.

It is generally easier to achieve goals that are at least partly aligned with the direction of national policy. For example, if the government is committed to improving cancer outcomes, a timely call for action on HPV-caused cancers might be taken more seriously. There may also be opportunities to focus on more technical policy reviews or consultations, for example, a NITAG or National Screening Committee review of national guidelines on HPV vaccination or cervical cancer screening. There may also be out-of-country policy initiatives, perhaps from the WHO regional office or the European Commission, that can influence the national policy debate.

In some countries, there may be greater concerns about equity and equality issues and, here, it may

help to incorporate arguments about fairness and justice into the case for gender-neutral vaccination. The need to protect men who have sex with men, who are more vulnerable to HPV infection, can also be included.

Cost will be a concern in many countries. Here, it may be necessary to convince decision-makers that acting to prevent HPV cancers (and other HPV diseases) now will save money in the long run. Not only will fewer people require expensive treatments but there will also be savings on welfare benefits and to employers. Health economics is a complex science and working with a health economist could be helpful.

It is also well worth exploring the issues that individual parliamentarians, or parliamentary groups, are interested in. Many parliaments have cross-party groups that focus on cancer or sexual health that might be interested in discussing or investigating HPV-related issues and publishing a report that raises the profile of the issue and creates new opportunities for advocacy.

Key questions include:

- Currently, what key policy issues are being discussed that could be aligned with action on HPV?
- Are there any national policy objectives – such as a commitment to tackle health inequalities – that can be used as policy levers?
- How can you address the financial issues to reassure politicians that improving vaccination or screening services will ultimately be an investment rather than a cost?

6. Develop a strategy and a budget

It may feel tempting to start campaigning as soon as possible but it is generally better first to spend some time developing a campaign strategy. This will enable you to identify where you need to focus your resources – which are likely to be less than you would ideally want – and what in practice you will do. Having a clear idea of the available budget – or having a feasible plan for fundraising – will also enable activities to be better matched with resources. It is worth remembering that campaigns that arouse strong passions can often call on volunteers with many key skills who will be willing donate their time and expertise at little or no cost.

ANALYSING THE POLICY LANDSCAPE – CASE STUDY

The HPV Prevention Policy Atlas, developed by EPF with the support of ECO, is a comparative map that scores 47 countries across geographical Europe on policies to prevent cancers caused by HPV. The Atlas focuses on HPV vaccination, cervical cancer screening and the provision of online information on HPV, cervical cancer and accessing vaccination. The Atlas highlights five 'champion' countries (headed by Denmark and Sweden) and eight 'exceptionally poor' countries (the lowest-scoring of which are Azerbaijan and Kosovo). The Atlas provides a very useful analysis of HPV policies in almost all European countries and has been used by EPF and ECO to make the case for action in those countries that are falling behind.

There are six broad targets for campaigning on HPV policy issues:

1. Scientists and clinicians, including GPs, nurses and pharmacists – getting experts 'onside' can be of critical importance as they will be advising or influencing decision-makers and can help to sway opinion in their local communities.
2. Policymakers – primarily officials responsible for advising government ministers and drafting official policy.
3. Politicians – parliamentarians, especially those from the governing party or parties, can be very influential with ministers.
4. The media – mainstream and social media coverage can influence the debate especially those media that are aligned more closely with the governing party.
5. Parents and young people – parents are the primary decision-makers about their children's vaccination and, if engaged in a campaign, could exert significant pressure on politicians while young people themselves can be an energetic, innovative and compelling voice for change.
6. Women – with cervical cancer the most common cancer caused by HPV, women's

organisations can constitute a powerful lobby for both vaccination and screening. There may also be men's organisations that can help to make the case for gender-neutral vaccination.

When seeking to convince policymakers, parents, young people and others of the need for action – and to help get coverage in the media – remember the power and potential impact of people's stories. The lived experience of those with a cancer caused by HPV can count for as much, if not more, than a hundred statistics.

Key questions include:

- Given the level of available resources for the campaign, which targets will have the biggest impacts?
- What are the most effective ways of engaging the key target audiences?
- What are good sources of personal case-studies?

DEVELOP A STRATEGY AND A BUDGET – CASE STUDY

The **HPV Coalition** in the UK invested heavily in the development of a strategy with the support of an expert advisory group, drawn from the Coalition's membership. A Roadmap report, containing the key campaign asks for the achievement of HPV cancer elimination, was developed and launched and was then presented to and discussed with a range of key decision-makers, including the Prime Minister's own health policy adviser as well as a wide range of parliamentarians. The campaign led directly to the National Health Service in England pledging to eliminate cervical cancer by 2040.

Journalists were identified as a key strategic target by the **HPV Coalition** in Bulgaria. It set up an 'Academy' for journalists with the goal of changing the narrative about HPV in the media. Journalists in Bulgaria are now reporting HPV issues more frequently and more accurately than ever.

7. Take action

Once the goals and objectives have been agreed and the strategy is in place, it is important to prepare an action plan which sets out what will be done, by who and when. A Gantt chart is one good way of showing the project schedule. A Gantt chart can easily be created on an Excel spreadsheet and shared with partners on Google Drive or a similar platform. The action plan should also record the outcomes of any activity, such as a meeting with a politician or a journalist.

When developing the action plan, it could be worth identifying 'hooks' for particular initiatives. World Cancer Day on 4 February each year provides a good opportunity as do International HPV Awareness Day on 4 March, World (and European) Immunisation Week in late April and Cervical Cancer Awareness Month in January.

Once action is underway, it is important for the leadership to report back to the executive committee and to the wider membership. This will help to clarify what tactics are proving effective – and which are not – and to adjust the approach where necessary.

Key questions include:

- Have you developed and agreed a coherent action plan?
- Do partners understand what they need to do and when?
- Is there a system for recording and reporting on actions taken?

8. Monitor and evaluate

Ideally, the campaign would appoint independent evaluators at the start who would track, monitor and evaluate throughout and end with a report on the outcomes and learning. However, this is likely to be beyond the financial means of most.

But this does not mean that nothing can be done. The establishment of SMART goals, the development of a strategy and the creation of an action plan provide a set of criteria against which progress can be measured. The executive committee and wider membership can also act as informal reference groups that can monitor developments and provide feedback and advice. And, at the end of the campaign, a range of partners could collaborate

TAKE ACTION – CASE STUDIES

International HPV Awareness Day, organised annually by **IPVS** since 2018, brings together over 140 organisations from around the world to create a coordinated global conversation about HPV and to share campaign materials that raise awareness of HPV and cancer with their communities. IPVS believes that awareness, education and reducing the stigma of HPV are important first steps in mobilising action to stop HPV. International HPV Awareness Day is always on 4 March.

HPV Action UK achieved high-profile coverage in a leading newspaper by releasing the text of an interview it conducted with Professor Harald zur Hausen, the Nobel Prize-winning scientist who discovered the link between HPV and cancer. Professor zur Hausen was quoted as saying that, 'in my opinion, the vaccination of boys is of the utmost importance because virus transmission is due to male partners and men are affected by oropharyngeal [cancers of the throat], anal and penile cancers as well as genital warts.'

ESGO's ENGAGE project has set up a Teens network. Created in 2020, this is a network of teenagers (aged 13–19) whose role is to spread awareness of HPV, vaccination and cervical cancer to other young people and to improve communication between the generations on HPV issues. The network is now active in 10 countries, including two outside of Europe.

A Vaccination and Prevention Summit was organised by **ThinkYoung** in Brussels in 2023. With 40 speakers and around 100 participants, the issues covered included the steps needed to enhance vaccination and prevention across the EU member states, how to develop successful communication campaigns on vaccination, and identifying best practices on vaccination and prevention.

on a project report or peer-reviewed paper that sets out what was achieved and what was learned.

Key questions include:

- Have you recognised the need to evaluate the delivery and, in particular, the impact of your advocacy work?
- Do you have a set of criteria against which success can be measured?
- How might you share your evaluation with partners and a wider audience?

MONITOR AND EVALUATE – CASE STUDY

After **HPV Action UK** wound itself up in 2020, having achieved its key objective, several of its key stakeholders collaborated on an academic paper describing every aspect of the campaign, analysing the enablers of success and highlighting the lessons learned.¹⁰ The paper was published in a peer-reviewed men's health journal. HPV Action's campaign director also contributed a shorter, more accessible version of the paper to the UK's leading dental journal.¹¹

Conclusion

It is entirely possible to envisage a world where all the cancers caused by HPV have been eliminated. HPV vaccination programmes – delivered on a gender-neutral basis to 90% or more of young people – supplemented by effective cervical cancer screening programmes (and, in time, quite probably by screening programmes for other HPV-caused cancers too) would be sufficient. But while the technologies that can deliver the goal of HPV cancer elimination already exist, they are too often being ineffectively implemented and, in too many countries, exist barely or not at all.

This is where advocacy can play a critically-important role. Civil society and professional organisations, together with individual opinion leaders, can work together to assemble the evidence, develop a strategy and take the action that will persuade politicians and policymakers to introduce the measures needed to prevent around 5% of all cancers.

Advocacy on HPV policy is now more than just a good idea. As this guide demonstrates, there is now solid evidence from campaigns across Europe that shows that advocacy can really work and result in less suffering and more lives saved.

Appendix

Participants

The organisations listed below participated in the Advocacy Symposium in January 2024 and supported the production of this guide.



Dance With Cancer Association (Turkey, USA)

Dance With Cancer, a non-profit organization based in New York that provides support and resources to cancer patients and their families in Turkey and the USA. Our Mission is to provide comprehensive and research based information for anyone affected by cancer through our website and online support platforms, in order to increase awareness around prevention and care as well as provide psychosocial support.



European Cancer Organisation (Belgium)

ECO's HPV Action Network was launched in December 2019. Its initial work was focused on influencing the development of the European Commission's Europe's Beating Cancer Plan and ECO believes that the inclusion in the Plan of a 'flagship' commitment to gender-neutral HPV vaccination was at least in part due to its campaigning. Since then, ECO has supported the development of HPV advocacy campaigns in Romania, Bulgaria and Croatia as well as the production and launch of the EPF/ECO HPV Prevention Policy Atlas in 2023. The elimination of all the cancers caused by HPV features largely in ECO's Manifesto, Time to Accelerate for Europe, which will be used to influence policy debates linked to elections to the European Parliament in 2024. ECO is also heading a major EU-funded research project on HPV vaccination, PROTECT-EUROPE, which will further inform its advocacy work. www.europeancancer.org



European Parliamentary Forum for Sexual and Reproductive Rights (Belgium)

Based in Brussels, EPF is a network of Members of Parliament throughout Europe who are committed to protecting the sexual and reproductive rights (SRHR) of all people, both at home and overseas. Since 2020, EPF has established the HPV Prevention Policy Atlas, a visual tool comparing policies on vaccination, screening and information in 46 European countries. The 2023 edition was elaborated in collaboration with ECO. EPF has successfully presented the Atlas and engaged with parliamentarians in more than 15 international events including in the European Parliament and the Council of Europe. Partnerships have been established with, among others, ECO, ESGO Patient Community, European Network of Gynecological Cancer Advocacy Groups (ENGAGE), UNFPA Eastern Europe Regional Cervical Cancer Prevention Alliance and the Global HPV Consortium. In 2023, EPF has presented the research in Georgia, Turkey, Serbia, at the World Health Summit in Berlin, Germany, in North Macedonia, at the European Cancer Summit and the European Cancer Forum in Brussels, Belgium. www.epfweb.org



Fondazione Veronesi (Italy)

Fondazione Veronesi is a non-profit organization created in 2003 by Professor Umberto Veronesi, an oncologist who dedicated his life to research and treating cancer patients. The Foundation supports scientific research in the field of oncology and promotes prevention campaigns to encourage people to lead a healthy lifestyle. In particular, Fondazione Veronesi raises funds to finance research projects with the aim of finding new cancer therapies that can be delivered to patients in a short amount of time and to identify new early diagnosis systems for all types of cancer. Fondazione Veronesi provides information and raises awareness among young people and adults about research and cancer prevention through meetings, workshops and campaigns promoting informed and healthy lifestyles. In addition, the

Foundation is engaged in advocacy activities at the national and European levels in the fight against smoking, HPV and in favour of health education in schools. www.fondazioneveronesi.it

HPV Action Romania

Supported by ECO, HPV Action Romania is helping national organisations and institutions to mobilise and join forces to implement policies aimed at increasing HPV vaccination, screening and information coverage. A wide range of organisations have come together as part of this new campaign. These supporters have agreed on a call to action on three fronts: (1) Routine gender-neutral HPV vaccination for all 11-18-year-olds with 90% uptake by 2030; (2) A national population-wide cervical cancer screening programme, based on HPV testing and including self-sampling as an option for hard-to-reach groups and others, with 70% of women screened by the age of 35 and again by age 45, to be achieved by 2030; and (3) A sustained public education campaign promoting HPV awareness, vaccination and screening. www.europeancancer.org/hpv/impact/hpv-romania



HPV Action (UK)

HPV Action was established in the UK in 2013 with the sole aim of achieving gender-neutral HPV vaccination. It grew quickly to represent over 50 organisations, large and small and from a wide range of backgrounds in cancer, sexual health, public health, oral health, men's health and elsewhere. While the focus of the campaign was the UK's NITAG (called JCVI, the Joint Committee on Vaccination and Immunisation), HPV Action's targets also included parliamentarians, scientists and clinicians, and the media. It used sex discrimination law to argue that it was unlawful for the government to deny vaccinations to boys. The campaign's advocacy work was entirely funded by its members and primarily conducted by a freelance health policy consultant. After five years of campaigning, JCVI decided that the HPV vaccination programme should be gender-neutral and boys have been vaccinated in the UK from 2019. HPV Action wound itself up shortly after achieving its goal.



HPV Coalition (Bulgaria)

The HPV Coalition was founded in March 2023 by distinguished experts in the fields of virology, oncology, paediatrics, public health and general medicine. United by the common cause of preventing the spread of HPV-related diseases, to protect public health and the future of the nation, the Coalition works purposefully with a range of partners including the European Cancer Organization and the country offices WHO and UNICEF in Bulgaria. The Coalition advocates for greater access to HPV vaccination for boys and girls in various age groups by steering professional debate with the medical community and the institutions. www.hpvcoalition.bg

HPV Coalition (Croatia)

The HPV Coalition is bringing together and supporting organisations by running advocacy campaigns which will make the case for faster progress on HPV vaccination and cervical cancer screening. With ECO's support, the Coalition was launched in December 2023 at the Croatian Parliament. www.europeancancer.org/hpv/impact/hpv-croatia



HPV Coalition (UK)

The HPV Coalition, established in 2022, is a group of charities, leading patient groups, professional groups, clinicians and expert individuals who have come together to inform and advance the UK's journey towards the elimination of HPV-related cancers. The Coalition recognises that whilst the UK has historically been a world-leader in the prevention of HPV diseases, significant challenges in recent years, exacerbated by the COVID-19 pandemic, have put this progress in jeopardy. Utilising the wealth of member knowledge at our disposal, a Roadmap to elimination has been developed for policymakers, providing recommendations across six themes which take aim at securing long-term reductions in HPV-related cancer incidence and mortality. This

marks the first step of concerted, but crucially collaborative, action towards making the elimination of all HPV-related cancers in the UK a reality.



International Papillomavirus Society (Switzerland)

IPVS was officially established in 2000 with the purpose of promoting the worldwide exchange of ideas, knowledge, and research materials among basic, clinical and public health research professionals concerned with human and animal papillomaviruses and their associated diseases. IPVS also strives to facilitate research and to promote the translation of research results into new clinical applications and public health policies. IPVS serves as the organisational structure for the field of biomedical scientists, physicians and other health care providers engaged in all manner of papillomavirus research. It also is a staunch advocate for additional papillomavirus research, public awareness of papillomavirus-related diseases and opportunities for prevention and management, and international education. www.ipvsoc.org



Karkinaki (Greece)

Since 2020, Karkinaki Awareness for Childhood and Adolescent Cancer has focused on raising awareness about HPV elimination. The campaign, 'Prevention is in your hands', was the first awareness campaign run by the organization from 2020 to 2023. The tools used were a website (www.stop-hpv.gr), a social media campaign, a brochure, graphic animation video, and six webinars about HPV vaccination. A national survey, 'Assessing knowledge, perceptions, and practices of the Greek population regarding Human Papillomavirus (HPV) and HPV vaccination', was run in 2022. The study aimed to evaluate the knowledge of the general population about HPV to obtain an estimate of the reported uptake of HPV vaccination and testing, and to identify the characteristics associated with lack of knowledge about HPV and vaccination for it. A new awareness campaign, 'Eliminate HPV ...', has

been launched in 2024. Karkinaki was the founding partner of the Hellenic Alliance Against HPV. The Hellenic Alliance is no longer active. www.karkinaki.gr



PASYKAF (Cyprus)

Founded in Cyprus in 1986 by 21 people with cancer experience and other devoted friends, PASYKAF has evolved into an organisation of thousands of members and supporters, providing professional health and home palliative care services to cancer patients as well as prevention programmes. PASYKAF has an active presence in local, European and international organizations, either by participating in the individual actions of these organizations or in meetings of their Boards of Directors on Local, European and international levels.



ThinkYoung (Belgium)

ThinkYoung is the first think tank focusing on young people. It was founded in 2009 in Brussels and has expanded to Geneva, Hong Kong and Nairobi. It is a not-for-profit organisation, with the aim of making the world a better place for young people, by involving them in decision making processes and by providing decision makers with high-quality research on key issues affecting young people. ThinkYoung conducts studies and surveys, makes documentary movies, writes policy proposals and develops educational programmes. So far, ThinkYoung projects have reached over 800,000 young people. In January 2019, ThinkYoung founded the ThinkYoung Vaccine Coalition, a group composed of 40 young health professionals representing more than 15 nationalities in 22 countries, who are engaged either in primary healthcare or health policy. The Coalition's main objective is to advocate for the importance of vaccination and prevention across Europe, both at the EU and national levels. www.thinkyoung.eu

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As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.

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