

Parliamentary Manual

THE ROLE OF PARLIAMENTARIANS IN CERVICAL CANCER PREVENTION





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Table of Contents

Table of Contents	
Abbreviations and Acronyms	4
Acknowledgements	5
About EPF Who we are What we believe	6
About UNFPA	7
Foreword	
About Cervical Cancer A. Facts about cervical cancer B. Figures on cervical cancer worldwide and Europe	9
Cervical Cancer Prevention A. Primary prevention and factors leading to HPV infection B. Secondary prevention	12
Successful Cancer Screening Programme: Planning & Implementation	
A. Organised versus opportunistic screening B. Case study C. Age for screening debut D. Key factors for both screening and vaccination E. Economic benefits of prevention intervention F. Workplace burden of condition/disease	

IV	Case Study - Ireland	20
V	Case Study - Georgia	22
VI	What Can Parliamentarians Do?	24
VII	Sample Parliamentary Questions to The Relevant Ministry	25
/111	Organisations Working on Cervical Cancer	26

Abbreviations and Acronyms

CIN	Cervical Intraepithelial Neoplasia	HR-HPV	High Risk Human PapillomaVirus
EPF	European Parliamentary Forum	IPPF	International Planned
	on Population and Development		Parenthood Federation
EU	European Union Institutions	MDG	Millennium Development Goals
	and Member States	NGO	Non Governmental Organisation
	of the European Union	SRHR	Sexual and Reproductive Health
HIV/AIDS	Human Immunodeficiency Virus /		and Rights
	Acquired Immunodeficiency	UK	United Kingdom
	Syndrome	UNFPA	United Nations Population Fund
HPV	Human PapillomaVirus	WHO	World Health Organisation
HIV/AIDS	and Member States of the European Union Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome	NGO SRHR UK UNFPA	Non Governmental Organisation Sexual and Reproductive Health and Rights United Kingdom United Nations Population Fund

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About European Parliamentary Forum on Population and Development - EPF⁽¹⁾

WHO WE ARE

EPF is a Brussels-based parliamentary network that serves as a platform for cooperation and coordination for the 31 all-party groups in Parliaments throughout Europe that focus on global health and particularly on improving sexual and reproductive health and rights (SRHR) at home and abroad. EPF seeks to empower Members of Parliament (MPs) in Europe to meet their international commitments to advocate for population and development issues in a national, regional and international setting. By offering MPs a framework for cooperation and debate at a pan-European level, EPF and its network of member parliamentary groups across the continent are able to effectively mobilise the resources to achieve the funding and policy commitments of the Millennium Development Goals (MDGs).

EPF's expertise derives from its exclusive focus on parliamentarians. Its core activities include conducting field visits to developing countries, supporting parliamentary activities, organising conferences on key topics and providing training to develop understanding and expertise in SRHR, HIV/AIDS, reproductive system cancers and other healthrelated issues.

EPF provides a pan-European framework for parliamentarians to forge consensus and collaborate on resource mobilisation strategies. EPF also frequently works with United Nations (UN)agencies, inter-governmental organisations and national, regional and international non-governmental organisations (NGOs) that have an interest in working with parliamentarians. EPF began as a project of the International Planned Parenthood Federation (IPPF) European Network. It was legally registered in Belgium and recognised by Royal Decree in 2000. In 2004, EPF became a fully independent not-for-profit organisation.

WHAT WE BELIEVE

EPF believes that parliamentarians have the opportunity and the responsibility to promote global health and, particularly, SRHR and gender equality, which are core elements of human dignity and central to human development.

¹⁾EPF website : www.epfweb.org

About United Nations Population Fund - UNFPA⁽²⁾



NFPA, the United Nations Population Fund, delivers a world where every pregnancy is wanted, every birth is safe and every young person's potential is fulfilled.

UNFPA is on the ground improving lives in about 150 countries worldwide and nearly 20 countries in Eastern Europe and Central Asia.

Working with governments, and through partnerships with other United Nations agencies, civil society, parliamentarians and the private sector, UNFPA strives to make a real difference in the lives of people, especially those most vulnerable.

Two frameworks guide its efforts: the Programme of Action adopted at the 1994 International Conference on Population and Development (ICPD) and the Millennium Development Goals (MDGs). The goals of UNFPA - achieving

universal access to sexual and reproductive health (including family planning), promoting reproductive rights, reducing maternal mortality and accelerating progress on the ICPD agenda and MDG 5 - are inextricably linked. UNFPA also focuses on improving the lives of youths and women by advocating for human rights and gender equality and by promoting the understanding of population dynamics. Population dynamics, including growth rates, age structure, fertility and mortality and migration have an effect on every aspect of human, social and economic progress. And sexual and reproductive health and women's empowerment all powerfully affect and are influenced by population trends.

⁽²⁾ UNFPA website : www.unfpa.org

Foreword

very year, some 32,000 women die of cervical cancer in Europe and Central Asia. Central and Eastern Europe is particularly affected: women in the Eastern part of the region are ten times more likely to die of cervical cancer than those in Western Europe. Cervical cancer is a deadly disease. But unlike other cancers, most cases – some 80% – can be prevented by putting in place the right policies and programmes.

Stepping up prevention has far-reaching benefits, in particular for young people. The cervical cancer epidemic has a "young face": it affects mostly young women, many of whom are in the process of starting families and building their careers. In many places, cancer treatment is extremely costly, leading to the impoverishment of entire families.

Members of Parliament are uniquely positioned to influence the shape and content of their countries' public health agendas. They can lead the development of relevant legislation and policies and monitor implementation; ensure oversight, accountability, transparency and good governance; make the voice of affected citizens heard; and define the fiscal and budgetary regimes needed to mobilise sufficient resources.

With the aim of generating support for prevention programmes, the European Parliamentary Forum on Population and Development (EPF) and UNFPA, the United Nations Population Fund brought together parliamentarians from Eastern and South-eastern Europe on 15-16 November 2012 in Prague, Czech Republic. The manual was developed as a follow-up to this meeting, designed specifically for parliamentarians willing to work on legislation and initiatives aimed at reducing the incidence of cervical cancer in their countries. This initiative was made possible thanks to generous financial support from the Ministry of Foreign Affairs of the Czech Republic.

We hope that this Manual will help Members of Parliament in the region to initiate, or intensify, work on advocating for and enacting effective cervical cancer prevention legislation and policies, thus contributing to long-term changes in the region's public health landscape.



Neil Datta Secretary European Parliamentary Forum on Population and Development



Werner Haug Director UNFPA Regional Office for Eastern Europe and Central Asia

A. FACTS ABOUT CERVICAL CANCER

The human papillomavirus (HPV) is the major cause of cervical cancer in women. It is a very common virus transmitted by skin-to-skin or sexual contact between men and women as well as same sex partners. Infection can persist for many years without symptoms and it is not possible to know when the infection occurred. There are more than 100 types of human papillomavirus. Some of these affect the genital area including the cervix. Cervical cancer is caused by any one of about 15 high-risk types of the human papillomavirus and around 80% of adults will have had an HPV infection at some time in their lives. The majority of infections occur in young people during their first few years of sexual activity with the incidence and prevalence then decreasing in older age groups. However 90% of new cervical HPV infections are cleared naturally by the immune system. In the remaining cases, HPV can cause the cells of the cervix to become abnormal and slowly develop into a cancer.

High risk HPV infection is most common in young women with peak prevalence as high as 25-30% in women under 25 years. Additional risk factors include: immunodeficiency, cigarette smoking, co-infection with other sexually transmitted infections (including HIV), herpes simplex virus 2, chlamydia and gonorrhoea. There are no obvious symptoms at the early stage of the disease. At advanced stages, the patient will experience vaginal bleeding after intercourse, unusual vaginal discharge and overall pain the genital area. Progression from abnormal cells to cervical cancer can take up to 10 - 20 years.

There are no treatments for cervical HPV infections but the CIN (cervical intraepithelial neoplasia) caused by these infections, if detected early, can be removed using simple and effective outpatient procedures.

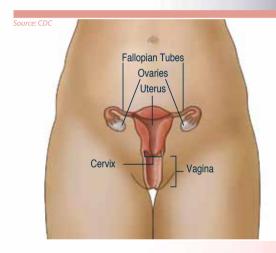
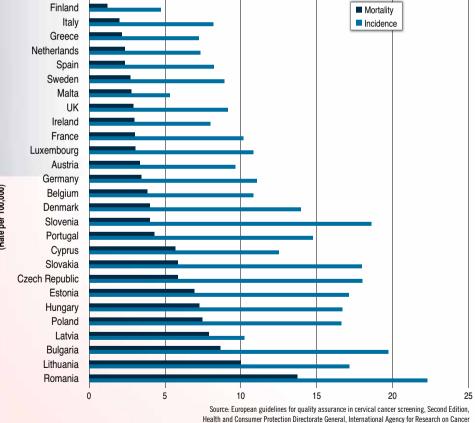


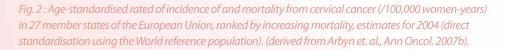
Fig. 1 : Progress from HPV infection to cancer



B. FIGURES ON CERVICAL CANCER WORLDWIDE AND EUROPE

Worldwide, cervical cancer is the second most common and the fifth deadliest cancer in women. Approximately 80% of cervical cancers occur in developing world and it is the leading cause of cancer death in adult women in the developing world. In 2008 it was estimated that there were 473,000 cases of cervical cancer worldwide and in 2010 there were about 225,000 deaths from the disease globally. Most cases occur in low and middle-income countries where there are no cervical cancer screening programs. For example, cervical cancer was responsible for 12% of new cancer cases in low-income countries, but only 1% of new cases in high-income countries. Yet in 80% of cases this disease could be prevented and deaths could be averted.





Rate per 100,000)

Each year in the WHO European Region⁽³⁾, there are around 60,000 new cases of cervical cancer while the disease typically causes the deaths of about 32,000 women. The risk of dying from cervical cancer is 10 times higher in Central Europe than in Western Europe.⁽⁴⁾ This is mainly due to the nationally organised screening programs or extensive opportunistic screening in Western Europe. Among this group of countries, the lowest incidence rates are found in Finland, Malta and Ireland. In contrast, recent years have seen a high and increasing incidence of the disease in Eastern European countries such as Romania, Bulgaria, Slovenia and Slovakia.

Cervical cancer has a "young face" and is the second most common cancer among women of 15-44 years of age - women who are busy with their careers, raising their families, or doing both. It therefore has far-reaching effects on the fabric of society.

⁽³⁾ The WHO European region entails: Albania, Andorra, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Herzegovina, Bulgara, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Gorgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Malta, Monaco, Montenegro, Netherlands, Norway, Poland, Portugal, Republic of Moldova, Romania, Russian Federation, San Marino, Serbia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, The former Yugoslav Republic of Macedonia, Turkey, Turkmenistan, Ukraine, UK of Great Britain and Northern Ireland, Uzbekistan

(4) Source: http://www.euro.who.int/en/health-topics/Life-stages/sexualand-reproductive-health/activities/cervical-cancer





CERVICAL CANCER PREVENTION

While there are no treatments for cervical HPV infections, the CIN (cervical intraepithelial neoplasia⁽⁵⁾) caused by these infections, if detected early, can be removed using simple and effective outpatient procedures. The oldest and most widespread screening test, created by Dr. George Papanicolaou, can identify changes in the cells of the cervix before one has symptoms. Therefore regular screening within organised programmes can reduce the risk of cervical cancer by up to 80%.

Prevention of cervical cancer can be divided into 2 pillars⁽⁶⁾:

Primary prevention:

- Vaccination against human papillomavirus prior to sexual activity;
- Education and awareness-raising to reduce high-risk behaviours (see next chapter).

Secondary prevention:

 Organised screening programmes targeting appropriate age groups with effective links between all levels of care.

HPV vaccination has been an important advance in the battle against cervical cancer. Together, organised cervical cancer screening and HPV vaccination will offer the most effective protection against cervical cancer.

(5) Cervical intraepithelial neoplasia (CIN), also known as cervical dysplasia and cervical interstitial neoplasia refers to abnormal changes in the cells on the surface of the cervix. The cervix is the lower part of the uterus (womb) that opens at the top of the vagina.

⁽⁶⁾ Comprehensive cervical cancer control. A guide to essential practice, WH0, 2006.

A. PRIMARY PREVENTION...

There are over 100 types of HPV, but two of them – HPV-16 and HPV-18 – cause 70% of cancers. Two vaccines are now available to protect against these two high-risk types of cancer: **Gardasil** and **Cervarix**. Both vaccines additionally protect against 80% of anal cancers, 60% of vaginal cancers, and 40% of vulvar cancers.⁽⁷⁾ Gardasil also protects against the two low risk HPV types (HPV-6 and HPV-11) that do not cause cervical cancer, but 90% of genital warts.⁽⁶⁾

The vaccination is most effective if given before a girl has been exposed to HPV, that is before she becomes sexually active, at about 11-12 years old. The vaccine is given in a three-dose series.⁽⁹⁾

A number of countries in Europe have introduced the HPV vaccine and 7 countries: **Denmark, Italy, Luxembourg, Portugal, Spain, Switzerland and the UK** have achieved coverage rates of 80% or more.⁽¹⁰⁾

When determining the exact year of **age for routine vaccination**, country-specific factors should be taken into consideration. These factors are¹¹:

- Average age of sexual debut;
- Age-specific prevalence of HPV infections (when available);
- Vaccine delivery strategies;
- Acceptance of vaccination by the target group (and their guardians).



Fig. 3 : HPV vaccine coverage, 2009

In terms of strategies of vaccine delivery (three doses of vaccine by injection to all recipients over a six-month period), the EU Guidance for the Introduction of HPV Vaccines provides an excellent overview of different modes, their advantages and disadvantages, which can be summarised as follows⁽¹²⁾:

(7) De Vuyst, H.; Clifford, G. M.; Nascimento, M. C.; Madeleine, M. M.; Franceschi, S. (2009). «Prevalence and type distribution of human papillomavirus in carcinoma and intraepithelialneoplasia of the vulva, vagina and anus: A meta-analysis». International Journal of Cancer 124 (7): 1626–1636. doi:10.1002/iic.24116. PMID 19115209.

⁽⁸⁾ HPV Vaccines». Centers for Disease Control and Prevention (CDC). 2010-10-15.

(9) WHO Europe Website

(10) WHO Europe Website

⁽¹¹⁾ European Centre for Disease Prevention and Control. Guidance for the Introductoin of HPV Vaccines in EU Countries, Stockholm, January 2008

(12) European Centre for Disease Prevention and Control, Guidance for the Introductoin of HPV Vaccines in EU Countries, Stockholm, January 2008, page 31

METHOD OF HPV VACCINE DELIVERY	ADVANTAGES	DISADVANTAGES
SCHOOL-BASED IMMUNISATION	 School attendance is mandatory in most of European countries. 	 Only administrable where school health services already established.
	2. Parents tend to trust and be in favour of school	 Payment may be difficult to collect if vaccine purchase and delivery are not centrally funded.
4	immunisation programmes. 3. Children are already in the school setting, keeping organisational costs low.	3. Parental consent may be difficult to obtain as parents are not normally present at the time of administration of the vaccine.
School-based imr	nunisation is likely to be the lowest cost op	tion in most places.
COMMUNITY BASED PRIMARY CARE	1. Availability in every country.	 Hard to monitor uptake and tracking.
HEALTH CLINICS	 Doctors and nurses are often well known and trusted by the local community. 	2. Young adolescents rarely visit clinics for reasons other than illness
	 It is possible to ensure medical and other personnel are well educated about, and willing to promote the use of HPV vaccines. 	 Increase of organisational costs, as clinics do not have the same coverage of a school.
	uld be good to deliver vaccines to the famil not likely to be effective disseminators for	
SEXUAL, REPRODUCTIVE HEALTH AND GYNAECOLOGICAL	 Provide services for sexually active individuals. They are useful for reaching 	 They are mostly used by women during or after first pregnancy, making it too late for optimal primary prevention.
SERVICES	the important "catch up" category – those who have not received the vaccine in another setting.	2. The access of adolescents and young women
	 They have the potential to provide combined immunisation and screening and have experienced staff. 	to those services is limited in many countries.
non-sexually activ	on, as the target population for HPV vaccines re people are unlikely to be accessing these s ammes and delivering information to the m	should not be sexually active and services. Such facilities could be used
OTHER SETTINGS: NON-HEALTH NON-SCHO	May be effective in targeting OOL 'hard to reach' individuals (children from difficult	May be costly and complex and require several different approaches to implement



This approach could be used to maximise the effect of school immunisation by reaching adolescents that are out of school.

... AND FACTORS LEADING TO HPV INFECTION⁽¹³⁾

The vast majority – 90% – of HPV infection will be cleared naturally by the immune system. Therefore in addition to being infected with the virus, behavioural and environmental factors contribute to the development of HPV infection. Educational campaigns promoting healthy lifestyle help reduce the risky behaviours contributing to the development of cervical cancer (smoking, young age of sexual debut, a high number of sexual partners and having partners with multiple partners). The below table summarises three types of co-factors that may facilitate cancer development.⁽¹⁴⁾

1. HPV-RELATED COFACTORS:

- 1.1 Viral type;
- **1.2** Simultaneous infection with several oncogenic types;
- 1.3 High amount of virus (high virus load).

2. HOST-RELATED COFACTORS:

- 2.1 Immune status: people with immunodeficiency, such as that caused by HIVInfection, have more persistent HPV infections and a more rapid progression to pre-cancer and cancer;
- **2.2** Parity: the risk of cervical cancer increases with number of children a woman has had.

3. EXOGENOUS COFACTORS:

- 3.1 Tobacco smoking;
- 3.2 Co-infection with HIV or other sexually transmitted agents such as herpes simplex virus 2 (HSV-2), Chlamydia trachomatis and Neisseria gonorrhoea; _____
- **3.3** Long-term (> 5 years) use of oral contraceptives⁽¹⁵⁾

(13) Source: Comprehensive cervical cancer control. A guide to essential practice, WHO, 2006.

⁽¹⁴⁾ Source: Comprehensive cervical cancer control. A guide to essential practice, WHO, 2006.

(15) A WHO expert group, convened to examine the evidence and formulate recommendations, concluded that all methods of contraception, including OCs, carry risks and benefits. With respect to cervical cancer, the benefits of OCs outweigh the risks, because the number of cervical cancers that result from their use is likely to be very small; therefore, women who choose to use OCs should not be prevented or discouraged from doing so.

B. SECONDARY PREVENTION

Human papillomavirus vaccines do not eliminate the need for cervical cancer screening, as about 30% of cervical cancers will not be prevented by the vaccines. Cervical cancer is the easiest female cancer to prevent with regular screening tests and follow-up. As it develops slowly, the screening has proved to be effective in reducing incidence rates.

Cervical cells can be normal, mild, moderate, severely abnormal or cancerous.⁽¹⁶⁾

Fig. 4: Cervical cells in three different stages

Normal cells



Normal and abnormal cells



Abnormal cells



There are several options for conducting cervical cancer screening:

1. Pap smear test is the oldest and most widespread screening test. It involves removing a sample of cells from the cervical epithelium and examining their morphology under the microscope in order to identify abnormal cells. Samples are smeared directly onto a microscope slide after collection. If an abnormality is detected and there is a need for further scrutiny, the patient may be referred to have a cervix examination by **colposcopy**.

2. HPV testing: As cervical cancer will not develop in the absence of a persistent infection with a high-risk HPV type, testing for the presence of HPV infection can be used to identify women who are at increased risk of developing cervical cancer.

3. A variation of the Pap smear test is **known as liquid based cytology and is primarily used in the UK**. Here, the Pap smear sample is put in a bottle containing a liquid medium that preserves the cells until transport to the laboratory, where it is then smeared on the slide.

4. In low-resource settings a visual inspection of cervix, using acetic acid (white vinegar/VIA) or Lugol's iodine, could be carried out. These substances highlight precancerous lesions so that the performing doctor, nurse, or midwife can see them with the naked eye.

⁽¹⁶⁾ The pictures were provided in the presentation of Hon.George Tsereteli, MP (Georgia) during the Parliamentary meeting « Strengthening Cervical Cancer Prevention in Eastern Europe and the Balkans » on 15–16 November, 2012, Prague, Czech Republic.

A. ORGANISED VERSUS OPPORTUNISTIC SCREENING

Cervical cancer screening can be offered either as **opportunistic screening** or as an **organised screening programme**. The organised model is considered preferable to opportunistic screening as it is⁽¹⁷⁾:

- More effective (producing the greatest reductions in cervical cancer);
- More equitable (providing the same benefits to all women);
- More efficient and cost effective (making the best use of available resources and reaching the greatest number of women).

Together, organised cervical cancer screening and HPV vaccination will offer the most effective protection against the disease.

However, both organised and opportunistic screening can fail because of poor qualitycontrol, low coverage of the population at risk, over-screening of low-risk populations and failure to follow-up.

In the European Region, Romania has the highest incidence and mortality due to cervical cancer, whilst Greece and Turkey have the lowest incidence. According to the Report on the Implementation of the EU Council Recommendations on Cancer Screening (2007), organised cervical screening programmes have been rolled out nationwide in the UK, Netherlands, Denmark, Sweden, Finland, Hungary, and Slovenia. In contrast, there are a number of countries in Europe which have undertaken opportunistic screening programmes and they are: France, Germany, Belgium, Czech Republic, Slovakia, Austria, Greece, Bulgaria.

ORGANISED SCREENING⁽¹⁸⁾

Organised screening is designed to reach the highest possible number of women at greatest risk of cervical cancer with existing resources. It is usually planned at the national or regional level. An organised screening programme should specify:

- The target population;
- Screening intervals;
- Coverage goals;
- A mechanism for inviting women to attend screening services;
- The screening test or tests to be used;
- The strategies to ensure that all women found positive on screening are informed of their result:
- A mechanism for referring women for diagnosis and treatment;
- Treatment recommendations;
- Indicators for monitoring and evaluating the screening programme.

OPPORTUNISTIC SCREENING

Opportunistic screening is done independently of an organised or population based programme, on women who are visiting health services for other reasons. Screening may be recommended by a provider during a consultation, or requested by a woman. Opportunistic screening tends to reach younger women at lower risk, who are attending antenatal, child health, and family planning services.

⁽¹⁷⁾ Information provided by Hon. George Tsereteli, MP (Georgia) during the Parliamentary meeting « Strengthening Cervical Cancer Prevention in Eastern Europe and the Balkans » on 15-16 November, 2012, Prague, Czech Republic.

⁽¹⁸⁾ Source: Comprehensive Cervical Cancer Control. A guide to essential practice. WHO

http://whglibdoc.who.int/publications/2006/9241547006_eng.pdf

B. CASE STUDY

Some of the most convincing evidence of benefits of organised cervical cancer screening programmes can be seen in the experience of three Nordic countries⁽¹⁹⁾ - Finland, Sweden and Iceland - which have data available from both before and after nationwide organised screening was implemented in the late 1960s.

All three countries have seen a tremendous decrease in both incidence and mortality, with the largest decrease seen in **Finland**, with municipality level invitational programme for women.

Here, the age-standardised mortality rates decreased by over 80%: from the level of 7.0 deaths per 100,000 in early 1960s to 1.2 deaths per 100,000 in the 1990s (rates adjusted for age to the world standard population).

In Finland, initially women aged 30-54 years were invited for screening at five-year intervals and in the early 1990s the age groups 55-64 were added to the programme. In Sweden and Denmark, which have partially organised programmes, the mortality rate decreased by 52% and 66% respectively.

(19) European guidelines for quality assurance in cervical cancer screening, Second Edition, Health and Consumer Protection Directorate General, International Agency for Research on Cancer, page 15.

Fig. 5 : Incidence

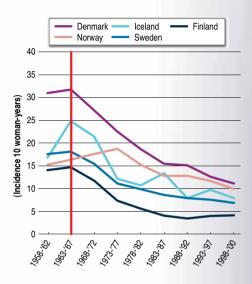
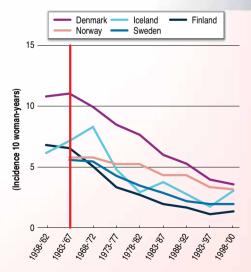


Fig. 6 : Mortality



C. AGE FOR SCREENING DEBUT

The Council Recommendation recommends cervical cancer screening for those ranging in age from 25 – 30 to 60 – 65. The Recommendation states that screening should start no earlier than 20 and no later than 30 years of age. There is no mention of when screening should cease. However, according to the recommendation by the Advisory Committee on Cancer Prevention, a body established by the Europe against Cancer programme, the upper limit should not be lower than 60 years.⁽²⁰⁾

In Europe, the age of first screening varies from 15 (Luxembourg) up to 30 (Estonia, Lithuania, Netherlands); while the age at which screening ends varies from 59 (Estonia, Poland) to 64 (Belgium, Italy, Portugal, Romania, etc.). With regard to the implementation of HPV vaccination in Europe:

- Organised HPV vaccination is conducted in: Spain, Portugal, UK, Ireland, Italy, Belgium, Netherlands and Romania;
- Opportunistic HPV vaccination is conducted in: France, Germany and Greece.

⁽²⁰⁾ Source: Advisory Committee on Cancer Prevention, 2000; Coleman et al., 1993).



D. KEY FACTORS FOR BOTH SCREENING AND VACCINATION

Public health programmes that effectively combine cervical screening with HPV vaccination could prevent the vast majority of cervical cancers. Key factors for both screening and vaccination are^[21]:

- They must be population-based;
- They need to ensure **high coverage** of the target population (>70%);
- They should ensure equitable coverage;
- They must provide an extensive quality assurance;
- They must foresee a **full integration** of the two programmes;
- Vaccination registry
 <-> screening registry

Without these elements, the programme will produce suboptimal reductions in cancer rates or no reductions at all, as well as increased morbidity and waste substantial health resources.

Introduction of the vaccine must be preceded by an educational campaign for the public, health care providers, journalists, etc. Information on vaccination for adolescents should be accompanied by information on screening for adults, and be done for all target audiences. Additionally, there should be a dedicated media monitoring and response capability. Finally all vaccinations should be recorded in a vaccination registry.

Screening is a public health process requiring the effective operation & interaction of multiple health services. Its implementation therefore requires a carefully planned process that builds capacity across all these services simultaneously.

⁽²¹⁾ Implementing Cervical Cancer Prevention as an Integral Part of the Health System By: Dr. Philip Davies, Director General, European Cervical Cancer Association.

E. ECONOMIC BENEFIT OF PREVENTIVE INTERVENTION

As with most preventive services, screening for and treating cervical cancer in its early stages is much less expensive than intervening at later stages in the disease process. The Pap smear has proven to be one of the most successful methods of cancer prevention and early detection available.⁽²²⁾ In addition to reduced medical care costs, the years of life gained from early detection and treatment are valuable to families, businesses and the community at large.⁽²³⁾

F. WORKPLACE BURDEN OF CONDITION/DISEASE

On average, 26.3 years of life are lost by each woman who dies of cervical cancer.^[24] Most cervical cancer cases occur between the ages of 20 and 50 years.^[25] These lost years of life - which often occur during the prime working years - translate into lost earnings for women and their families, worker-replacement costs for businesses and are a significant cost to society.^[26]

(22) National Cancer Institute. SEER Stat Fact Sheets: Cervix Uteri. http://seer.cancer. gov/statfacts/html/cervix.html. Accessed March 27, 2012.

⁽²³⁾Brown ML, Lipscomb J, Snyder C. The burden of illness of cancer: economic cost and quality of life. Annu Rev Public Health. 2001;22:91–113.

(24) Howlader N et al. SEER Cancer Statistics Review, 1975–2008, National Cancer Institute. Bethesda, MD. http://seer.cancer.gov/csr/1975_2008/, based on November 2010 SEER data submission, posted to the SEER web site, 2011. http:// seer.cancer.gov/csr/1975_2004/results_merged/topic_year_lost.pdf. Accessed February 23, 2012.

(25) American Cancer Society. Detailed guide: Cervical cancer: What are the key statistics for cervical cancer? http://www.cancer.org/Cancer/CervicalCancer/ DetailedGuide/cervical-cancer-key-statistics. Accessed March 27, 2012.

⁽²⁶⁾Brown ML, Lipscomb J, Snyder C. The burden of illness of cancer: economic cost and quality of life. Annu Rev Public Health. 2001;22:91–113.



ш 19

Case Study – Ireland: CervicalCheck National Programme

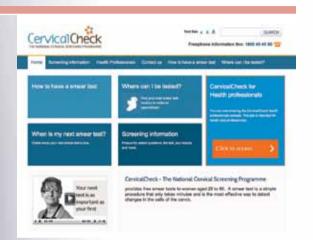


Fig. 7 : CervicalCheck website, www.cervicalcheck.ie.

efore the launch of the Cervical Cancer Prevention programme in Ireland, the trend in mortality from cervical cancer since 1978 has been increasing by 1.5% per year (2005). In 2005 alone, 252 women were diagnosed with cervical cancer and more than 90 women died from the disease. Average age of death was 56 years old. Cervical cancer represented **second most common cancer** in women under 44 years old.⁽²⁷⁾

To respond to this growing threat, the government in 2008 launched the **national screening programme**, *CervicalCheck*. This decision was preceded by pilot screening programmes in 2000 following the ministerial decision to establish the national programme.

CervicalCheck is a national, population-based, quality assured cervical screening programme that offers population-based screening programme built on the integration of administration, primary care smear-taking, cytology and colposcopy. *CervicalCheck* operates through a **register** of eligible women nationwide aged 25 to 60 that it has developed through cooperation with the Department of Social Protection as well as from self-registration and colposcopy details. Each three year screening round, a woman received **a call, a re-call or an invitation letter** by post to invite her to a smear test. The test is offered free of charge for women aged 25-64. *CervicalCheck* has also developed a strategy to inform, educate and encourage women to participate.⁽²⁸⁾

⁽²⁷⁾ Pnformation providedby Mr. NiallBehan, Chief Executive Irish Family Planning Association ⁽²⁸⁾ Website of CervicalCheckhttp://www.cervicalcheck.ie/

"The successful introduction of an organised, well-managed, national cervical screening programme has the potential to reduce current incidence rates from cervical cancer among women in Ireland by up to 80%. There are approximately 76 deaths from cervical cancer annually in Ireland."

Case Study – Ireland: CervicalCheck National Programme

After two negative smear tests with **three years** apart, the women are switched to a five yearly smear test invitation. Results are provided to women within 4 weeks.⁽²⁹⁾

In the first 3 years 60% of the eligible population has been screened, with 84% of smear test results being negative (normal). Women with abnormalities received necessary treatment.

The key learning from Ireland can be formulated in the points outlined below:

- Reputation of the programme is the key;
- The programme has become hugely popular;
- The programme makes a significant impact over time;
- Integrative approach is required;
- There is a need to **set targets** for all elements of the programme.

Some of the principal **challenges** and barriers hindering women's access to screening include: **fear, anxiety, intellectual and physical disabilities, language barriers and literacy difficulties**. The Irish National Cancer Screening Service has developed a comprehensive communication and screening promotion approach to educate, inform and encourage women to participate in screening.

Information leaflets in 12 different languages and in Braille are available and have simple content and messages. Additionally, *CervicalCheck* offers the support line *Freephone* which receives over 1,000 calls per week.⁽³⁰⁾

(29) Website of CervicalCheckhttp://www.cervicalcheck.ie/
 (30) Cervical Check Programme Report 1 September 2010 – 31 August 2011.



Fig. 8: Information leaflets for CervicalCheck

Case Study – Georgia

he Georgian Cervical Cancer Screening Programme aims to increase the detection of cervical cancer at the early stages in order to reduce the early mortality of women caused by this disease through ensuring equitable access for the women of the target ages to cervical cancer screening services.

BACKGROUND INFORMATION

Breast and cervical cancers are the most common forms of cancer among Georgian women and major causes of morbidity and mortality of women of reproductive age.⁽³¹⁾ Up until 2006, the Government of Georgia had been allocating funds only for treatment of cancer diseases at stages III and IV within the framework of the State Oncology Programme, which did not envisage any investments in prevention and early detection of the disease. As a consequence, during this period, according to the national statistical data, almost 77% of new incidents of cancers were detected at the III-IV stages, when the treatment is the least effective.

As a result of UNFPA/Georgia advocacy efforts, in 2006 the Municipality of Tbilisi launched the pilot project on Reproductive Tract (RT) cancer prevention and early detection, which was implemented through the co-financing agreement between UNFPA and the municipality. At the beginning of 2008 UNFPA succeeded in bringing the issue of the importance of increasing state funding for RT cancer prevention and early detection to the top of the Reproductive Health National Council's agenda and strongly advocated for expansion of the ongoing project. This effort yielded excellent results and in 2008, based on the analyses of the achievements of the pilot project and accumulated experience, the project was redesigned to focus on breast and cervical cancer screening for the targeted population in Tbilisi and National Screening Centre was selected as Implementing Partner of the project.

COMPONENTS

• Cervical cancer screening organised according to the National Guidelines for the target age group of women in the capital Tbilisi;

 National capacity building for provision of quality services in terms of cervical cancer screening;

 Population behaviour change campaign targeted at the general public to raise the awareness of the population on cancer prevention and early detection and about benefits of cervical cancer screening.

RESULTS

 Georgia Cervical Cancer Screening programme is a well established one, based on the national guidelines for the quality assurance, developed within the framework of the project and approved by the government;

• Annually, more than 30,000 women benefit from cervical cancer screening services;

• As a result of implementation of the screening programme, cancer detection at early I and II stages has increased within the frames of the programme and reached almost 81% of all detected cases;

• The quality of provided services has improved significantly through a series of capacity building trainings and seminars, provided by the leading European technical institutions in the field, on Pap test methodology and cytological diagnostics, cervical cancer screening quality assurance principles for the RH service providers, as well as for cyto-pathologists involved in the screening programme;

 The demand for the screening services has increased during the last two years, resulting from the massive information-education and behaviour-change communications campaign conducted within the frames of the project; this included airing of the PSA with popular role models on TV channels, outdoor

Case Study – Georgia

advertising through placing the banners on the public buses and the busiest subway stations, organising TV talk-shows, publishing articles in popular magazines, distributing specifically developed flyers and booklets, organising promotion events, etc. In response to the increased demand for information, the project established the inter-active website (http://gnsc.ge);

• The remarkable achievements of the project, contributing to the reduction of women's morbidity and mortality, prompted the federal government to decide to replicate the project at the national level - since October 2009 the breast cancer screening programme has been operational in four regions of Georgia. The project has also been expanded in Tbilisi through opening of the National Screening Centre's new branch in the city;

 The project gained a regional recognition by receiving the "Pearl of Wisdom" award at the Cervical Cancer Prevention Summit, organised by the European Parliament, European Cervical Cancer Association and Politicians for Cervical Cancer Prevention in January 2009;

 Regional partnership has been fostered with the establishment of the Black Sea Countries Coalition on Breast and Cervical Cancer Prevention to support member countries in advancing breast and cervical cancer prevention and early detection efforts;

 This cost-effective project has all the attributes to become one of the most successful cases in the region and serve as a pilot project for future experience and knowledge sharing.

KEY ELEMENTS OF SUCCESS

• The success of the project owes much to the partnership between UNFPA/Georgia and the government. This is the only project where the government co-finances the RT cancer screening in partnership with UNFPA. Government funding continues to increase each year and in 2010 its overall contribution increased by 34%; • Strong managerial support provided by UNFPA and its efforts to develop local capacities for screening project management positively affected the efficiency and cost-effectiveness of the project;

 Strong emphasis on the national capacity development for quality assurance and provision of quality screening services is another determinant of the success;

• The project serves as basis for collection and analyses of data to identify priorities and to inform future planning.

LESSONS LEARNED

 Government commitment is crucial in initiating the screening programme and ensuring its sustainability in addressing the alarming rates of women's morbidity and mortality caused by reproductive system cancers;

• Without national capacity development on quality assurance of screening services and management of the programme, the success could not have been achieved;

• One of the main lessons learned is the importance of regional partnerships, which led to establishment of partnerships between Georgian and European institutions, creation of the Black Sea Coalition on Breast and Cervical Cancers Prevention to further generate political support and maintain government commitment.

⁽³¹⁾ Breast cancer in 2008 was reported 42 cases per 100,000 women and cervical cancer - 10 cases per 100,000 women.

What Can Parliamentarians Do?

his section provides examples and ideas of initiatives that can be undertaken by APPGs, parliaments and parliamentarians in order to foster greater awareness and resource mobilisation for cervical cancer prevention issues.

1. TAKE ACTION

 Organise informal parliamentary meetings with Members of Parliament supportive of preventing cervical cancer, followed by a Parliamentary Hearing in the relevant Committee with the purpose of raising awareness among Parliamentarians and enabling them to negotiate with the Ministry of Finance;

 Take an active part in discussion supporting the budgetary allocations for cervical cancer screening and vaccination programmes during budget votes on the state level and municipal level;

 Participate actively in parliaments throughout the region, in the Cervical Cancer Prevention week, which takes place each January;

 Campaign for free screening programmes with engagement of professional groups and CSOs;

 Become a strong voice in building public awareness about cervical cancer and calling for greater government leadership and investment in preventing and controlling the disease;

 Discuss with local authorities the cervical cancer prevention activities and the availability and quality of treatment services in the region.

2. BE ACCOUNTABLE

 Engage in the issue as a means of strengthening the prevention programmes and reducing mortality in their district.

3. COLLABORATE

 Work with the national Ministries of Health and encourage relevant actors to start collaborating with the WHO on receiving technical expertise in legislative and programmatic issues;

 Send a joint letter to GAVI Alliance Board for support to introduce the HPV vaccine in the country;

 Use the experience of international partnerships, such as Black Sea Cancer Coalition, AURORA and public-private partnerships in designing national programmes on cervical cancer prevention.

4. DEMONSTRATE YOUR COMMITMENT

 Organise or participate in press conferences and other media events aimed at raising awareness of cervical cancer and encouraging women to attend screening;

 Advocate for media engagement in reducing stigma, gender and social barriers that may hinder access to services among the target population;

• Table parliamentary questions to the relevant Ministries about the state of the implementation of the vaccine and screening in the country.

5. CREATE VISIBILITY

 The Pearl of Wisdom was created as a unique symbol the public can use to identify the Cervical Cancer Campaign. Now, over 1.5 million Pearl of Wisdom pins have been distributed across Europe and they have become a key part of the events held during the Cervical Cancer Prevention Week (CCPW).



Fig. 9:The Pearl of Wisdom

Sample Parliamentary Question to The Relevant Ministry

hese questions could be tabled both at federal and local parliaments in the parliamentary constituency, thus providing the opportunity to find solutions both at national and regional levels.

QUESTION 1:

To request the Government to provide information on the country situation by answering the following questions:

- Is cervical cancer a major national health problem?
- What are national and sub-national incidence and mortality rates attributed to the cervical cancer?
- Are specific populations more at-risk?
- How do national rates compare to other countries in the region?

QUESTION 2:

Request the Ministry of Health to respond to the following questions:

- What are the screening and treatment outcomes in the country?
- What is the awareness level of the disease among the population and health professionals?
- Are the two HPV vaccines registered in the country? If yes, who is currently accessing the HPV vaccine and at what cost?
- Is the HPV vaccine available at subsidised cost to those who cannot afford it?
- What is the average age of sexual debut?
- What is the average age of girls or women who are getting vaccinated against HPV?

QUESTION 3:

Which national or sub-national cervical cancer advocacy or education efforts are underway? What is the level of awareness among women and girls, parents and general public?

QUESTION 4:

Organised cervical cancer prevention programmes can prevent up to 80% of new cases of this disease and prevent the deaths of women in the prime of their lives. Does the Government plan to launch vaccination and screening programmes during (add year) given the fact that cervical cancer mortality in (add country) is 10 times higher than in the countries with organised prevention programmes?

QUESTION 5:

In (add year) the Ministry of Health launched a pilot project for cervical cancer screening in (add region of the country) for women from 25 to 65 years old. When does the Government plan to scale up the HPV vaccination to cover the entire country, given the fact that only population based organised screening programmes will produce tangible results for the entire population of the country?

QUESTION 6:

In (add year) (add the donor: GAVI, EU, any other) will graduate its programme on HPV vaccination in (add region and country). What is the Government planning to do to ensure the sustainability of this life-saving vaccination programme and its further scale up throughout the whole country?

Organisations Working on Cervical Cancer Prevention:



WHO – WORLD HEALTH ORGANISATION



UNFPA – UNITED NATIONS POPULATION FUND

WHO is the authority responsible for public health within the United Nations system. The WHO Regional Office for Europe (WHO/ Europe) is one of WHO's six regional offices around the world.

It serves the WHO European Region, which comprises 53 countries, covering a vast geographical region from the Atlantic to the Pacific oceans. WHO/Europe is made up of public health, scientific and technical experts, who are based in the main office in Copenhagen, Denmark, in 4 outposted centres and in country offices in 29 member states.

WHO/Europe provides technical support to help countries make evidence-based decisions on introduction of HPV vaccine and evaluate the cost of introducing the vaccine along with cervical cancer screening, and can assist in assessing the readiness of and strengthening school immunisation programmes to administer HPV vaccinations.

WHO/Europe also assists countries in evaluating the introduction of HPV vaccine, and achieving and maintaining high coverage rates once it is part of routine vaccine programmes.

More at: www.euro.who.int

UNFPA is an international development agency that promotes the right of every woman, man and child to enjoy a life of health and equal opportunity. UNFPA supports countries in using population data for policies and programmes to reduce poverty and to ensure that every pregnancy is wanted, every birth is safe, every young person is free of HIV/AIDS and every girl and woman is treated with dignity and respect. Two frameworks guide its efforts: the Programme of Action adopted at the 1994 International Conference on Population and Development and the Millennium Development Goals, eight targets to reduce extreme poverty by 2015.

UNFPA supports the prevention and treatment of sexually transmitted infections, including HPV.

More at: www.unfpa.org

Organisations Working on Cervical Cancer Prevention:

International Agency for Research on Cancer

World Health Organization

IARC – INTERNATIONAL AGENCY FOR RESEARCH ON CANCER, LYON, FRANCE

The International Agency for Research on Cancer (IARC) is the specialised cancer agency of the World Health Organisation with an objective to promote international collaboration in cancer research. The Agency is inter-disciplinary, bringing together skills in epidemiology, laboratory sciences and biostatistics to identify the causes of cancer so that preventive measures may be adopted and the burden of disease and associated suffering reduced.

The Agency has a particular interest in conducting research in low and middle-income countries through partnerships and collaborations with researchers in these regions.

The IARC has an important role in describing the burden of cancer worldwide, through cooperation with and assistance to cancer registries and in monitoring geographical variations and trends over time. Key publications include the Cancer Incidence in Five Continents series and GLOBOCAN.

Cancer of cervix is one of the research topics of the IARC.

More at: www.iarc.fr/en/cancertopics/ cervixtopics.php. The mission of the ECCA is to raise awareness of cervical cancer and its prevention among members of the general public, healthcare professionals and public health decision-makers in Europe.

The ECCA is a large network of organisations and individuals from across Europe that have joined forces to prepare and distribute evidence-based information on the causes of cervical cancer and the importance of organised cervical cancer prevention programmes in the prevention of this disease. In 2013, the membership of the ECCA exceeded 120 institutional members (cancer societies, medical associations, research organisations and patient groups) from 34 countries together with more than 5000 individual members from 40 countries.

ECCA also awards The Pearl of Wisdom award and by 2013 over 1.5 million Pearl of Wisdom pins have been distributed across Europe and numerous patient groups, cancer societies, medical associations, etc. have included the Pearl of Wisdom in their Cervical Cancer Prevention Week events.

More at: www.ecca.info/the-ecca/the-ecca

ECCA – THE EUROPEAN CERVICAL CANCER ASSOCIATION

viii 27



Organisations Working on Cervical Cancer Prevention:



GAVI ALLIANCE – GLOBAL ALLIANCE ON VACCINATION AND IMMUNISATION



IPPF - INTERNATIONAL PLANNED PARENTHOOD FEDERATION

The GAVI Alliance is a public-private global health partnership committed to increasing access to immunisation in poor countries. The Alliance brings together developing country and donor governments, the World Health Organisation, UNICEF, the World Bank, the vaccine industry in both industrialised and developing countries, research and technical agencies, civil society, the Bill & Melinda Gates Foundation and other private philanthropists.

Thanks to the GAVI Alliance, the poorest countries have access to a sustainable supply of HPV vaccines for as low as \$US 4.50 per dose (in 2013), which can cost more than \$100 in developed countries. Tajikistan and Uzbekistan are among GAVI eligible countries from EECA region. Support is provided in response to country proposals, which are reviewed by an independent group of experts - mostly health officials from developing countries.

More at: www.gavialliance.org

IPPF works in 172 countries to empower the most vulnerable women, men and young people to access life-saving services and programmes, and to live with dignity.

Supported by millions of volunteers and 30,000 staff, IPPF Member Associations provide sexual and reproductive health information, education and services through 65,000 service points. Those services include family planning, abortion, maternal and child health, and STI and HIV treatment, prevention and care.

The International Planned Parenthood Federation European Network (IPPF EN) is one of six regions of IPPF and includes 40 Member Associations in as many countries throughout Europe and Central Asia. The Region reaches from Iceland to Kyrgyzstan and from Russia to Israel, from some of the richest countries in the world to some of the poorest, from donor countries to recipient countries, from long standing democracies to countries still struggling to find their way.

More at: www.ippfen.org/about-us



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