Indian Cancer Society

The Indian Cancer Society (ICS) is the first NGO in the cancer space established in 1951 by Dr. D.J.Jussawalla and Mr Naval Tata. It has been doing sterling work in fighting cancer across India. Headquartered in Mumbai, ICS has branches at Delhi, Bengaluru, Nagpur, Kolkata, Patna, and Lucknow. ICS has pioneered the cancer registry process in India by establishing the first population-based cancer registry in Mumbai in 1963. It promotes awareness about cancer, its risk factors, preventive measures, need for screening and early detection, financial support for treatment and managing life post treatment.

ICS is committed to advancing the WHO goals of the global control of cervical cancer by adopting strategies suitable to the Indian subcontinent.

Burden of cancer of the cervix in India

Cancer of the uterine cervix is a public health challenge in India, which accounts for one-fifth of the world’s burden of this cancer. It is the second leading cause of cancer incidence and mortality in Indian women after breast cancer. This is a cancer that occurs significantly around age 45 and peaks at age 55, affecting women when their families are most vulnerable to their maternal functions.

In 2012, there were 1,22,844 cervical cancer cases in India and 67,477 deaths from the disease [1]. in 2020 the corresponding number was 1,23,907 and 77,348. The numbers tell the depressing story that nothing much has changed [2]. Cancer of the cervix still remains amongst the most common cancers in India and a leading cause of cancer-related mortality in women. It is small comfort that India shares the world cervical cancer burden with other low and medium-income countries (LMIC) where both the incidence and deaths from the disease surpass those in the more developed world. All LMICs have populations that are socio-economically and educationally vulnerable and an overburdened health infrastructure where late diagnosis and poor access to treatment make cervical cancer a national health problem.
Why Cancer of the cervix?

Breast cancer is today the leading cancer in women worldwide so too in India. Why then should the government or NGOs be focussing their attention on cancer of the cervix? The answer lies in the well recognized facts about cervical cancer that make it an eminently preventable disease (Table 2.)

1. The natural history of the disease has been known for decades. There is a long precancerous phase lasting anything up to 10 years.
2. There are a proven screening methods that can be used in a population-based program to detect and treat this stage of the disease, viz. visual inspection and acetic acid (VIA) and the PAP smear, together with colposcopy and Loop electrosurgical excision procedure (LEEP).
3. The recent understanding that greater than 90% of the common cervical cancers are caused by high risk variants of the human papilloma virus (HPV) acquired through sexual intercourse.
4. The cervix is at its most vulnerable to HPV infection in young women in their teens and early twenties.
5. HPV can be detected by examining cervico-vaginal secretions by molecular tests which are very accurate.
6. An effective vaccine against the high-risk strains of HPV.

Trends in cervical cancer incidence in Indian population-based cancer registries (PBCR)

The disappointing story about the burden of cervical cancer in India must be tempered by the fact that many population-based cancer registries (PBCRs), including the Mumbai Cancer Registry the first PBCR in India, show decreasing trends in cervical cancer incidence [3]. The declining trend has been achieved despite the absence of an organized public health screening program. This speaks for factors other than screening that have brought about this downward trend. Chief amongst these, is the empowerment of women who have slowly but surely taken control of their own lives. There are now more women employed in the organized sector. Their aspirations for a better quality of life have inevitably led to a better socioeconomic status, postponement of the age of marriage, and fewer pregnancies, all of which constitute strong risk factors for cervical cancer.

Risk factors for cervical cancer

Although the major contributing factor is persistent infection by high-risk human papilloma virus (HPV), other factors also contribute to the development of cervical cancer, viz. age at the time of marriage or first sexual activity, number of pregnancies, genital hygiene, sexually transmitted infections like Chlamydia, Herpes simplex, unsupervised use of oral contraceptives, nutritional status...
and habits such as smoking. In remote rural areas, illiteracy, poor hygiene and a poor health infrastructure are often the primary reasons for the rise in incidence.

**The Role of Prevention and Screening for cervical cancer**

**Primary prevention**: Cancer of the cervix was one of the first cancers to be shown to have a long precancerous stage during which the chance of spread is negligible. Cancer is prevented by detection and elimination of the precancerous stage. This is known as primary prevention. Until the discovery that HPV was the cause of almost all cancers of the cervix, detection of precancer or cervical intraepithelial neoplasia (CIN) by the PAP test, VIA and other such modalities, was the only primary prevention that was available. Today, testing of vaginal secretions for HPV and vaccination against HPV offer more robust methods of primary prevention.

**Vaccination** is a recently introduced intervention for primary prevention, which has yet to take off in India due to cost constraints and acceptance issues around the vaccination of girls in the age group 9-14. The rationale for vaccinating girls at this age is that they should be protected before their first sexual encounter with the virus. The government is yet to roll out a subsidized vaccination program. However, the vaccine is licensed for use and can be administered by family practitioners, gynaecologists and paediatricians on demand. Ideally, awareness of the vaccine and its efficacy should precede the roll out of the vaccine. This is where well crafted, non-threatening messaging, aimed at parents, schools, paediatricians and family practitioners would help to sensitize urban and rural populations to this preventive intervention.

**Secondary prevention** is a term used to denote detection of a very early cancer, so called “early diagnosis”. This cancer is confined to a small area and is likely to be cured if treated effectively. In the cervix, these cancers are often detected at stage 1 when treatment may involve surgery, radiation therapy or both. Except for the morbidity of the treatment which may have side effects, the patient is unlikely to die of her cancer.

**Screening strategies**: Despite the high prevalence of cervical cancer in India, and the immense possibilities for primary prevention and early diagnosis of this disease, there has been no countrywide government sponsored public health policy on prevention by screening for precancer or early diagnosis.

According to NFHS-5 data the percentage of women who have ever undergone cervical cancer screening in India is miniscule: 1.9% (2.2% urban and 1.7% rural) [4]. Women living in the urban regions of Mizoram, Himachal Pradesh, Kerala, and Maharashtra have a higher number of women undergoing a screening test for cervical cancer. Paradoxically, rural women in Andhra Pradesh, Bihar, Jammu and Kashmir, Telangana, and West Bengal participate in higher numbers than those in urban areas [5]. Cervical cancer screening is close to insignificant in Nagaland, Ladakh, and Gujarat.

The most effective strategy for prevention of cervical cancer, up to the present time, is systematic screening of women aged between 30-69 years together with an organised program of treatment and follow up of screen detected lesions. The global WHO strategy encourages a minimum of two lifetime screens with a high-performance HPV test by age 35 and again by age 45 years. Precancers rarely cause symptoms, which is why regular cervical cancer screening is important, even if you have been vaccinated against HPV [6].

**The PAP test** is the most used test in the western world. However, it is very dependent on trained cytotechnologists and or cytopathologists for its efficacy. These are not easily available in India and other LMICs.
**VIA:** Visual inspection with acetic acid (VIA) is a naked eye examination of the uterine cervix after application of 5% acetic acid and interpreting the result after one minute. This is a simple and inexpensive test with moderate sensitivity and specificity for screening of precancerous cervical lesions and early invasive cancer. The result of the VIA test is immediately available. It does not require any laboratory support [7]. Capacity building for VIA along with access to the screen and treat approach is limited.

**HPV testing:** The recently introduced testing of cervico-vaginal secretions for HPV by molecular techniques is a very effective method for identifying women at risk for cervical cancer. The test can be performed by community health care workers or by women themselves in the privacy of their homes. The current limiting factor for the dissemination of this screening test is its cost and the need for transportation to a centre where the actual molecular testing is done by a validated laboratory.

**End to end strategy:** Detection of individuals with high-risk HPV, pre-cancer, or early cancerous lesions is only the beginning of the prevention pathway. All screen detected women must be directed to a centre where they will be counselled, examined and be treated appropriately. If this important step is missed, the entire population screening exercise is at risk. There is no greater tragedy than a woman who tests positive in a screening program developing a full-blown cancer through neglect of this vital step.

It cannot be over emphasized that every screen detected individual who is lost to follow-up is a looming disaster. Hence every organized screening program should have a built in “navigation” program for such individuals.

**Evaluation of efficacy:** It cannot be assumed that the act of screening a population has met its purpose at the conclusion of the screening exercise. Every program must be monitored for its failures and successes, so that strategies can be revised and implementation made as foolproof as possible.

**Opportunistic screening:** Many NGOs offer screening camps for a variety of diseases including cancer. Many are held for underprivileged communities. Unless these communities are visited repeatedly and all the principles of screening are effectively carried out, these are merely expensive ways of creating awareness. They should be avoided.

**Cervical Cancer Awareness in the population**

Doctors and researchers are agreed that cervical cancer is a national tragedy. They emphasise the need for population-based interventions to reduce the overall burden. One of the most urgent is creating awareness in the population, especially in vulnerable communities. Spreading awareness should go hand in hand with access to prevention and treatment facilities.

**WHO sets the goal**

The World Health Assembly adopted a global strategy to accelerate the elimination of cervical cancer as a public health problem for the period 2020–2030. In 2021, at the height of the pandemic, the WHO still found it imperative to give a clarion call for the elimination of Cervical Cancer as a major health hazard for women across the globe. The formula called for

- 90% of pre-pubertal girls between ages 9-14 years to be vaccinated by the HPV vaccine.
- 70% of adult women to be screened using high performance tests (HPV DNA) twice in their lifetimes - once before age 35 years & once at age 45 years.
• 90% of women with pre-cancer lesions treated & 90% of women with invasive cancer to be managed by treatment.

The goal was to avert 74 million new cases and 62 million deaths in 78 LMICs and to bring the incidence of Cervical Cancer below 4 per 100,000 in a community setting. More importantly, to maintain the numbers consistently [8].

**Indian Cancer Society Goal:**

The ICS goal is to create sufficient awareness of cervical cancer and its control, through hygienic practices, early detection through systematic screening of large defined populations and disseminating information about HPV virus and the HPV vaccine.

ICS strives to

1. Consistently conduct impactful and effective awareness campaigns through all forms of media (especially digital) on cervical cancer control.
2. Create awareness on menstrual and genital hygiene, safe sex and to educate the public about HPV and the availability of the HPV vaccine.
3. Establish the most cost effective and efficient screening protocol for detection of cervical cancer and facilitate screening of defined populations and keeping opportunistic screening to the minimum.
4. Develop strategic collaboration with key organizations that are working to eliminate cervical cancer in India viz. Federation of Obstetrics and Gynaecological Societies of India, the Association of Paediatrics and Adolescent Education, and other such bodies, to act as voice multipliers in carrying the message to schools and colleges across the country.
5. Pursue efforts with the State Governments that show interest for promoting sensitivity amongst primary health workers, parents, and teachers on cervical cancer control through Satark and other programs.
6. Extend the ICS-Satark program on education of health care professionals at grass root level to cover cervical cancer.
7. Add cervical cancer as one of the major modules in the ICS-Medical Education Program for the family physicians.
8. Create awareness through including a specific section on cervical cancer in the ICS-Mobile apps on cancer.
9. Create a special awareness module for schools and enlist schools through ICS branches and on-line platforms for dissemination of useful and catchy awareness material in English and local languages.
10. Keep track of the research studies in India and abroad on cervical cancer and HPV vaccine to explore cost effective interventions for prevention and early detection among the underprivileged.
11. Continue to track the trends in incidence and mortality through its registry and other research sources and publish the same.
12. Advocate the setting up of many more rural population-based registries in India as it is has been observed that registry activity not only increased cancer awareness among population, but also increased the early detection and thereby decreased mortality from cervical cancer.
Appendix 1

Government Initiatives

- 1975 Launch of the National Cancer Programme
- 1984 Revision of strategies and emphasis on primary prevention and early detection.
- 1990-91 District Cancer Control Centres are launched.
- 2004 Programme is revised again.
- 2009 HPV vaccine introduced in India. Delivery programme started in 2 States.
- 2010 Vaccine program was withdrawn.
- 2016 After a review by an expert group, the Ministry of Health recommended that all adolescent girls between ages 9-13 be vaccinated with 2-doses of HPV Vaccine. This first of its kind programme was launched in Delhi and taken up in Punjab and Sikkim.
- 2017 An expert committee recommended that the Ministry of Health & Family Welfare (MoHFW) include the HPV vaccine in the universal immunization program. in 2018, MoHFW decided against it, citing budgetary constraints as the reason. The affordable indigenous vaccine now offers a solution to this problem.
- In February 2018, the Government of India announced the creation of 1,50,000 Health and Wellness Centres (HWCs) by transforming the existing Sub Centres and Primary Health Centres. These centres are to deliver Comprehensive Primary Health Care (CPHC) bringing healthcare closer to the homes of people.
- 2022 An indigenous quadrivalent vaccine produced by the Serum Institute of India at an affordable price was launched.

Government of India response in early 2023

a. National Technical Advisory Group on Immunisation (NTAGI) decided to add HPV vaccine to the National Immunization Programme.

b. To start with girls between ages of 9-14 years will be vaccinated in 2 doses.

c. Six States - Karnataka, Maharashtra, Tamil Nadu, Uttar Pradesh, Mizoram & Chhattisgarh will start the roll out.

d. Cost to the Govt will be ₹200-400 per dose. It is likely to cost ₹2000 - ₹4000 in the open market. (This roll out has been delayed).

e. Catch up doses of girls aged 15 years plus, can happen later.
Appendix 2

Challenges and Barriers to Vaccination

Stakeholders such as Clinicians, Parents and Public Health Departments including the Department of Education, and NGOs have identified a variety of barriers to a mass–vaccination program.

1. The lack of information and knowledge about both the vaccine and its connection to Cervical Cancer is the most common barrier. Parents of adolescent children reject the idea that their children are sexually curious and therefore at risk HPV infection.
2. Because of this stigma, adolescents are reluctant to discuss their queries even with a trusted adult.
3. Doubts about the efficacy of the vaccine and possible side effects.
4. Fear of adverse side effects; like pain, fever and even infertility
5. The high cost of the vaccine is a deterrent to parents and government alike.

Appendix 3. ICS HQ and Branches initiatives

Indian Cancer Society’s initiatives for cervical cancer prevention and screening

Indian Cancer Society has been doing sterling work in fighting cancer across India. Headquartered in Mumbai, ICS has branches at Delhi, Bengaluru, Nagpur, Kolkata, Patna & Lucknow. ICS has pioneered the cancer registry process in India by establishing the first population-based cancer registry in Mumbai in 1963. ICS promotes awareness about cancer, its risk factors, preventive measures, need for screening and early detection, treatment options and managing life post treatment. It has pioneered the rehabilitation of women with cervical cancer through prosthesis support activities since 1970. Vaginal dilators are produced on the ICS premises and given free of cost or at a subsidised rate to patients referred from various hospitals.

Project SATARK aims to spread awareness and develop capacity amongst front line healthcare workers at PHCs with an aim to create awareness, reduce fear and encourage the population to stay two steps ahead of cancer. It focuses on oral and cervical cancers. The total number of women screened for cervical cancer in FY 22-23 is 45929 (HQ+ Branches). VIA has been used in the majority, followed by the PAP test and more recently HPV DNA detection. Of the women screened, 1274 were found to be screen positive and have been referred for further management.

ICS Delhi branch initiatives for cervical cancer prevention and screening

ICS Delhi started its intervention in cervical cancer quite early when it realised that cervical cancer was one of the cancers amenable to early detection and prevention. The PAP test was adopted in 1999 where gynaecologists and government hospitals were invited by the Delhi branch to join in detecting and treating cervical lesions. The doctors and hospitals helped generate awareness and the Delhi branch undertook free screening. So far, since the start of the program nearly 100,000 women have been screened.
References:


   https://www.ncdirindia.org/All_Reports/Report_2020/default.aspx


8. WHO Global strategy to accelerate the elimination of cervical cancer as a public health problem https://www.who.int/publications/i/item/9789240014107
