

# Cervical cancer: Misperceptions and under-reporting in Uganda

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# Presentation overview

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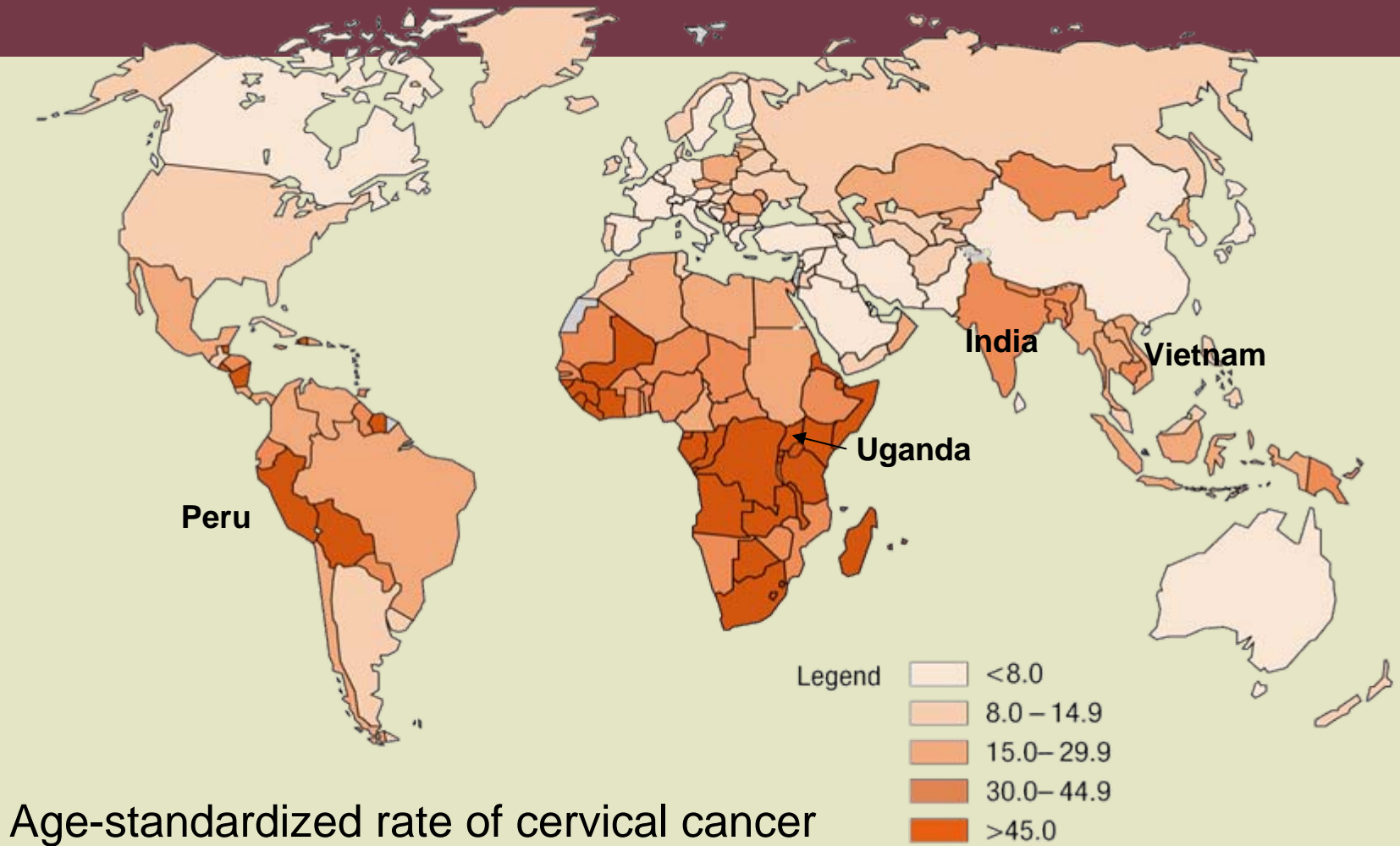


# Introduction

- In Uganda, cervical cancer accounts for over 80% of female cancers.
- Very limited pre-cancer screening programs in the country, with only about 5% of women having access.
- Availability of the HPV vaccine has opened a window for cancer prevention and control
- PATH working in four developing countries to generate data relevant to HPV vaccine introduction
- The data will also help governments make decisions about vaccine introduction
- Formative research was undertaken in 2007 in preparation for the MoH/PATH HPV vaccine demonstration project.



# Four project countries in demo



source: WHO/EIP Burden of Disease Projection—  
<http://www.who.int/healthinfo/statistics/bodprojections2030/en/index.html>



# Rationale for the formative research

- Aimed at understanding the medical, socio-cultural, policy and fiscal environments as well as health systems environment around cervical cancer and its prevention
- Two vaccines—bivalent and quadrivalent—are available globally – Cervarix™ and Gardasil®
- Both vaccines protect against oncogenic HPV-16 and -18, exhibit some cross-protection against other oncogenic types, and are very safe and well-tolerated.
- Challenges exist with the delivery of the vaccine to pre-adolescent girls in developing countries, where vaccines normally are targeted at infants.
- PATH is studying delivery mechanisms for the HPV vaccines, the costs of delivery, coverage, acceptability, messaging, feasibility, cost and socio-cultural issues.



# Methods

- In Uganda, five districts were selected from the five regions.
- Qualitative data collection methods were used, e.g. key informant interviews and focus group discussions
- Interviewees included:
  - Community level – 10 year old girls (in and out of school), their parents, their teachers, opinion leaders, district health workers and other officials
  - Focus group discussion also included boys
  - National level – policy makers and officials from line ministries such as Ministry of Health, Ministry of Education and Ministry of Gender. Also, other key stakeholders such as Members of Parliament.
- Hospital and clinic records also were reviewed, including observation of essential activities related to vaccinations.



# Results

- Public and professional knowledge about cervical cancer and its prevention is limited, often inaccurate
- Cervical cancer often confused with uterine cancer
- Early cervical cancer symptoms often confused with other STIs, leading to incorrect diagnosis
- Patients usually present with cervical cancer only in very late stages—treatment is not effective then
- Even in the capital city, many women are not screened in time and develop late-stage cancer
- Women with cancer suffer stigma and die at home without their illness ever being recognized or reported as cervical cancer



# Beliefs and misconceptions

- Negative beliefs about cervical cancer causes discourage community and individual mobilization for prevention and treatment services. People believe that:
  - Cervical cancer is a disease of prostitutes and those having too much sex
  - It is caused by poor hygienic practices
  - Cancers – including cervical cancer – cannot be prevented or treated so screening is a waste of time.
  - Cervical cancer's cause is unknown, and has no cure nor prevention. Its God's disease, once it comes, it comes.
  - Other attributed causes include untreated STIs, having sex during menstruation, and use of poor quality pads.



# Uganda Cancer Registry

- National-level data come primarily from the cancer registry
- The registry only records cases from the capital city area, representing less than 5% of the total population.
- Most women who die from cervical cancer in Uganda will never be recorded in the registry.



# Why is cervical cancer less known or less reported?

- Early stage screening services are very limited, but even the few are under-utilized.
- Health practitioners often misdiagnose early cancer cases as STIs.
- Stigma attached to cervical cancer and its symptoms leads patients to keep quiet.
- Noticeable symptoms only appear in later stages of cancer.
- Poor health-seeking behaviors
- Competing individual health and other financial priorities.



# What needs to be done?

- Train health workers on screening and treatment
- Sensitize community members and policy makers
- Need to strengthen the registry to capture a representative sample of the cancer burden in Uganda
- Formulate policies that would favor a good environment for prevention and control
- Stimulate political will to introduce cheap single-visit screening and treatment options such as VIA
- Generate support for sustainable HPV vaccination programs



# Implications for the HPV vaccine demonstration project

- Building awareness about the disease that is less known and attaches stigma is needed in advance of HPV vaccine introduction.
- Service delivery challenges exist—the vaccine is for girls whereas most vaccines in developing countries are targeted at infants.
- Undercounting can influence decision-makers' perception of cervical cancer as a health priority; could negatively affect efforts to strengthen prevention services, including vaccination.
- Policy/financing efforts are underway to reduce delays in making vaccine affordable and broadly available.



# Formative research outcomes into the demonstration project

- Vaccine delivery strategies suggested by respondents are now being tested in the field
- Communication strategies and messages have been developed based on FR results
- The Ministry of health is now taking a lead role in cervical cancer awareness and prevention.
- Stakeholders' are getting together to design strategies to prevent cervical cancer



# Screening is still needed

- For sexually active women likely already exposed to HPV (they are not appropriate for vaccination).
- For vaccinated women, to protect them from cancer caused by other HPV types.
- To monitor the impact of the vaccine and other control efforts.
- PATH is involved in strengthening current screening initiatives, including field use of a new, less expensive HPV DNA test.



# Conclusion

- Cervical cancer is a major but hidden women's health problem in Africa. Low levels of pre-cancer screening result in higher incidence of late stage cancer and death.
- Deaths of women from cervical cancer are unrecognized by the community and undercounted by the health care system, resulting in an under-estimation of the national burden of cervical cancer.
- To gain support for improved services, the magnitude of cervical cancer in Uganda and in other low-resource countries must be accurately assessed.
- HPV vaccines—combined with screening—offer great promise for eliminating inequity of cervical cancer burden.
- Building awareness about the disease is needed in advance of HPV vaccine introduction.
- In two years time, we will have strong data on how to best introduce the vaccine in Uganda, data that also will be valuable for other countries in the region.



# Web resources



**RHO CERVICAL CANCER**

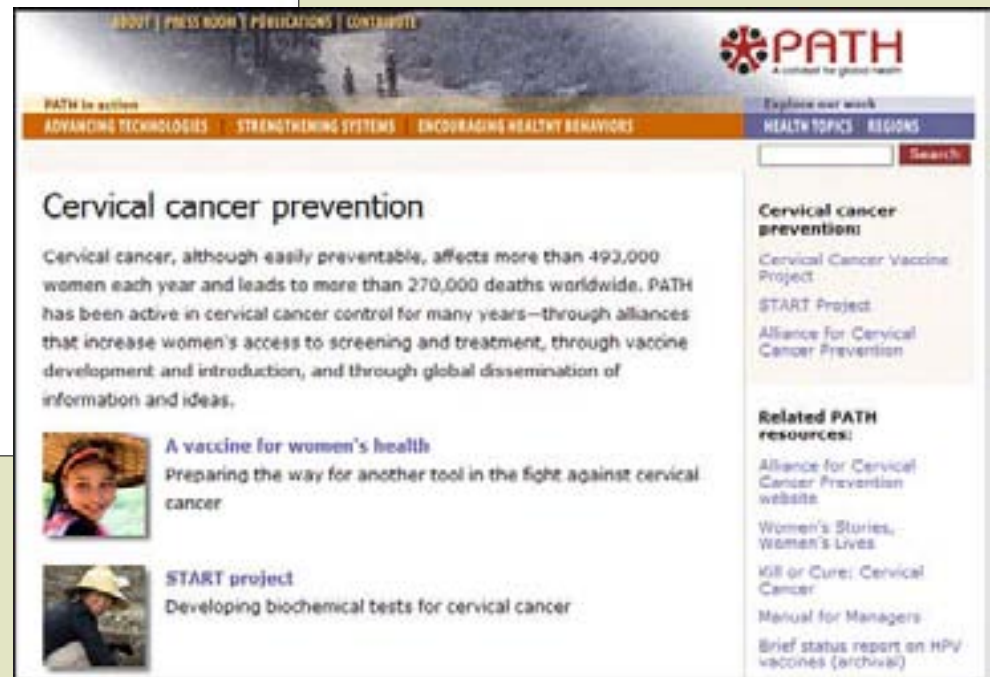
[About cervical cancer](#) | [Cervical cancer library](#) | [RHO archives](#)

## Cervical cancer library

- [General cervical cancer resources](#)
- [Vaccination](#)
- [Screening and treatment](#)
- [Advocacy, policy, and financing](#)
- [Adults, teens, and communities](#)
- [Training](#)
- [Cervical cancer organizations](#)
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## Cervical cancer prevention

Cervical cancer, although easily preventable, affects more than 492,000 women each year and leads to more than 270,000 deaths worldwide. PATH has been active in cervical cancer control for many years—through alliances that increase women's access to screening and treatment, through vaccine development and introduction, and through global dissemination of information and ideas.

-  **A vaccine for women's health**  
Preparing the way for another tool in the fight against cervical cancer
-  **START project**  
Developing biochemical tests for cervical cancer

### Cervical cancer prevention:

- [Cervical Cancer Vaccine Project](#)
- [START Project](#)
- [Alliance for Cervical Cancer Prevention](#)

### Related PATH resources:

- [Alliance for Cervical Cancer Prevention website](#)
- [Women's Stories, Women's Lives](#)
- [Kill or Cure? Cervical Cancer](#)
- [Manual for Managers](#)
- [Brief status report on HPV vaccines \(archival\)](#)

[www.path.org/cervicalcancer](http://www.path.org/cervicalcancer)



Thank you!

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