FORMATIVE RESEARCH: CERVICAL CANCER

Trinidad and Tobago, 2018

Trinidad and Tobago (2018): Formative research to develop promotion and communication strategies to increase preventive and treatment services for cervical cancer

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INTRODUCTION

Around the world, a woman dies of cervical cancer every two minutes, making it the fourth most common female cancer and the leading gynecological cancer globally. Each year, roughly 528,000 cases of cervical cancer are detected, and of those, 266,000 women die of the disease.[1] More than 85% of new cases and deaths occur in less developed countries, partly because routine cervical cancer screening and treatment are not widely available. Unless cervical cancer prevention and control measures are successfully implemented, it is estimated that by 2030, 800,000 new cases of cervical cancer will be annually diagnosed. Many of these cases will be in developing countries.[2]

The Caribbean region has some of the highest rates of cervical cancer worldwide (36 per 100,000 women),[3] and Trinidad and Tobago, has one of the highest cancer mortality rates in the region. Cervical cancer is the most frequent cancer among women aged 15-44 and the second leading cause of cancer death, after breast cancer in the country.[4] The World Health Organization (WHO) has estimated that 549,000 women over the age of 15 are at risk of developing cervical cancer in Trinidad and Tobago.[5]

The tools used to eliminate cervical cancer, including Human Papilloma Virus -HPV- vaccines, screening, and treatment for pre-cancerous lesions and early cancers already exist in the region; however, they are not being efficiently or effectively deployed to reach the half-million girls and women who are at risk in Trinidad and Tobago today. National efforts are underway to improve coverage of both screening and vaccination programs. In 2015, the Government of Trinidad began a school-based program offering HPV vaccine at no cost. Vaccine uptake to date in Trinidad has been slow, which reflects a broader trend of global vaccine uptake in which only 6.1% of females aged 10-20 years have been vaccinated against HPV[6].

In 2017, Population Services International (PSI), through Maverick Collective, launched a program to increase screening and vaccine coverage in the country. As part of these efforts, the PSI-Caribbean (PSI-C) team conducted formative research to better understand and document the local context and the information needs of girls, women, parents, and other stakeholders to improve the uptake of both primary prevention methods (HPV vaccine) and secondary prevention (cervical cancer screening and preventive treatment); and explored the barriers to uptake and delivery of cervical prevention methods, and opportunities to overcome these barriers from multiple perspectives.

The insights gathered from this research will be used to aid the development and implementation of effective strategies to increase the uptake of primary and secondary prevention methods and improve the technical capacity of health care providers to effectively deliver these services.

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[1] International Agency for Research on Cancer (IARC), GLOBOCAN 2012: Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012. *http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx.*

[2] World Health Organization. 2016. Introducing HPV Vaccine. Accessed online at: http://www.who.int/immunization/documents/ISBN_9789241549769/en/

[3] Chekuri A., Bassaw B., Affan A.M./ Habet G., Mungrue K. Knowledge, attitudes, practice on human papilloma virus and cervical cancer among Trinidadian women. *Journal of Obstetrics and Gynaecology,* 2012; 32: 691-694.

[4] Ibid.

[5] HPV Information Centre. 2017. Human Papillomavirus and Related Report. Trinidad and Tobago. Accessed online at: vi http://www.hpvcentre.net/statistics/reports/TTO.pdf

[6] Bruni L, et al. Global estimates of human papillomavirus vaccination coverage by region and income level: a pooled analysis. ***Lancet Glob Health*** **2016; 4: e453–63.**

While the main purpose of the research is to inform the development of program and marketing activities, it is also intended for key insights to be shared with national and international stakeholders. To this extent, other organizations or platforms that may be embarking on similar projects, can learn from the insights gathered as part of this study.

METHODOLOGY

Formative research was implemented in Trinidad and Tobago (i.e., Port of Spain, Point Fortin) using qualitative methodology, that included 9 focus group discussions (FGDs) with pre-adolescent and adolescent girls, parents, and women; and 14 in-depth interviews (IDIs) with healthcare providers and key stakeholders (see table). Participants were selected using convenience sampling, following the eligibility criteria detailed in the protocol. The study was submitted for ethical approval to the PSI Research and Ethics Board.

Target group	Activity	No. of activities	Description of activities
Girls	FGD	3	One FGD with pre-adolescent girls (9-12 years of age) from public school, and two with adolescent girls (13-16) from public and private schools.
Parents	FGD	3	Two FGD with mothers from public and private schools, and one with fathers.
Women	FGD	3	One FGD with women in their 20s, one with women in their 30s and one with women in their 40s.
Health care providers	IDI	6	Health care providers (e.g., gynecologists, OBGYN, pediatricians, nurses) from the public and private sector.
Stakeholders	IDI	8	Stakeholders from national and international health organizations and the education sector.

FGDs were conducted by the Pan American Social Marketing Organization (PASMO)[7] regional research team at four schools (two public and two private) and two community centers where meetings with women and fathers were organized. The discussion guides explored participant´s perspectives about vaccination, cervical cancer, HPV vaccine, and screening methods (in the case of women). In addition, recommendations were sought to promote the HPV vaccine, and cervical cancer screening.

IDIs were conducted by the PSI-C local team in participants´ workplaces. Questions were designed to elicit their perceptions about women´s health and cervical cancer in Trinidad and Tobago, and their recommendations for what can be done to promote HPV vaccine and cervical cancer screening. In addition, healthcare providers were asked about their experience with these services; and stakeholders about the national priorities of cervical cancer prevention.

All FGDs and IDIs were audio-recorded and transcribed verbatim in English. Audio files were coded using a standard coding framework though OneNote software.

[7] PASMO is an organization made up of social marketing professionals, passionate about sustainably contributing to the health of vulnerable populations. PASMO's programs are implemented through innovation, are evidenced-based, and results-oriented. PASMO has a local presence in every Central American country and forms part of the global network of PSI.

RESULTS

Key insights that emerged from the analysis are presented across six key themes (organized from general-to-specific order): health, cancer, cervical cancer, HPV vaccine, cervical cancer screening, preventive treatments. Recommendations provided by the participants and about the 4Ps (i.e., product, place, price, promotion) of marketing were added to the HPV vaccine and cervical cancer screening section.

Health

#1 - Women neglect their health, put themselves last

Women are usually preoccupied with daily activities, work, and family issues. No matter their situation, they often see themselves as caregivers and focus on the well-being and health of others. Women are the ones taking children for vaccines or ensuring their husbands go for regular check-ups. Stakeholders, health care providers, and women who participated in the activities emphasized that women need to start taking more care of themselves and their health.

#2 - Sexual and reproductive health issues are women´s main health concerns

Women are generally concerned about sexual and reproductive health issues, although their apprehensions vary by age. For example, women in their 20s mentioned that there is lack of follow-up for women in the health care system, especially in family planning services; women in their 30s revealed that reproductive difficulties, polycystic ovary syndrome (PCOS) and fibrosis are age-related reproductive health concerns; and women in their 40s expressed nervousness about menopause and their struggle to accept it.

> *"It never crossed my mind…I feel like the same person I was 20* [years ago] *…physically I don´t really feel like I reached the age where it crossed my mind that -yeah, something is happening here-, and then all of the sudden you feel that you are engulfed in flames."* (FGD – Woman in her 40s)

Cancer was also mentioned by women in their 30s and 40s, but at a lesser degree. The later, were the only ones who expressed concern for breast and ovarian cancer. Cervical cancer was not mentioned spontaneously by any age group.

#3 - Non-communicable diseases have captured public´s attention

Some stakeholders believe that non-communicable diseases (NCDs), or as a participant called them *"lifestyle diseases"*, have captured the public´s attention. There is high level of awareness of cardiovascular diseases, diabetes, and hypertension. People seem more willing to conduct regular screening assessments for NCDs than for specific types of cancer. Furthermore, in the social and

marketing environment there is a constant push to reduce NCDs risk factors by eating healthier, being more physically active, and losing weight; but the benefits that could have on cancer prevention are often left out. This was also corroborated with the health concerns that women in their 30s that mentioned hypertension and diabetes.

> *"The fact of being fat, pays more attention to the prevention of cardiovascular diseases. When people tell you to lose weight, it's because it is better for your heart, not because it is better for cancer."* (IDI, Stakeholder 5)

Cancer

#4 – The term "cancer" generates negative associations

There was a visible and audible reticence among women, girls and men when addressing cancer, possibly denoting fear of the disease. Most of those who participated in the activities shared that they have known someone who suffered cancer, making them extremely conscious of the disease and its impact at the different levels (e.g., individual, family).

Death, fear, isolation, suffering (of patient and family), physical pain, expense, weight loss, and hair loss were some of the ideas mentioned when asked to express what comes to mind when they hear the term "cancer". A sense of hopelessness*, "oh God, what am I going to do,"* and lack of control was also perceived among participants when talking about this disease. This view of cancer is often reinforced by society, that could impede the adoption of cancer-preventive behaviors.

#5 - Breast cancer is top-of-mind

Some stakeholders mentioned that breast cancer is the leading cause of cancer in the Caribbean. It also gets the most attention and was the most mentioned among the participants during the activities (i.e., women, men, girls), compared to the other types of cancer. Women seemed more comfortable talking about this type of cancer, and knowledgeable about its causes, screening tests, and treatment.

Breast cancer is heavily marketed. For example, Scotiabank has organized for 19 years, the Women Against Cancer 5K in Trinidad and Tobago. Funds from this event are used to cover the cost of free breast cancer screenings, mammograms and ultrasounds at selected health centers and specialist clinics in the month of October (breast cancer awareness month).

Stakeholders and health care providers believe that cervical cancer is *"underrated"* and not as salient in people´s minds. There are no advocates for cervical cancer, no events, no cervical cancer awareness month or prominent people talking about it. A stakeholder explained her frustration when comparing it to breast cancer:

"Cancer for breasts is sexier than cancer for cervix, and this is the struggle I have because we don´t have [preventive] *treatment for cancer for breasts, to the extent that we have preventive treatments for cancer for cervix."* (IDI – Stakeholder 5)

Cervical Cancer

#6 – Women receive cervical cancer information from several sources

There is no specific source from which women have acquired information about cervical cancer. They shared a variety of experiences of how they were first exposed: when they were told about the pap smear, looking at online sources to broaden the information provided by the health care providers, reading leaflets provided in the health centers and hospitals, volunteering at the Family Cancer Society, researching the different colors of cancer, and watching a Grey´s Anatomy episode were a woman was suffering from cervical cancer. Most women agreed that health care providers don´t take enough time with them to discuss cervical cancer, and the topic is only introduced if broached by them. Some women in their 30s shared that they default to looking for information online.

According to several stakeholders, several women don´t know that cervical cancer is highly preventable and that is caused by a virus that is sexually transmitted (i.e., HPV). Also, they are not aware of the seriousness of cervical cancer and importance of having regular pap smears. Some of the women who participated in the focus groups knew about HPV and its sexual transmission, and several prevention methods (i.e., vaccine, pap smears, ultrasounds, vaginal swabs). However, knowledge about treatment options in case of an abnormal pap smear is lacking. Women in their 30s mentioned: remove the womb, *"scrape things or parts inside you,"* chemotherapy, surgery, etc.

#7 - Genetic predisposition is seen as a possible cause of cervical cancer

There are several misconceptions about what causes cervical cancer. Even though some women shared that it can be caused by HPV or by a *"virus transferred through sexual intercourse"*, the idea that it can be hereditary or caused by certain types of foods that people eat (e.g., processed foods) still lingered among participants (e.g., women, men, girls). Therefore, removing the womb if a woman has a genetic predisposition (like the mastectomy available for women who inherit breast cancer high risk), and eating healthier to reduce *"cancer cells from growing"* were some of the ideas that were articulated when discussing treatment options. This shows that at a certain level, participants are mistakenly thinking of cervical cancer the same way they think of breast cancer.

#8 - Cervical cancer, still hush-hush

People are not talking about cervical cancer and are keeping it private. Women have heard or know women who have gone through it, especially women in the older cohort (40-year-olds). However, men did not know women affected by cervical cancer and assume that it is because women don´t talk about it in their presence.

"... [Cervical cancer] is still a taboo, a big, big taboo. You can never know how prevalent it is because people keep it…very hush-hush." (FGD – Mother, Public School)

Some health care providers believe that people relate this type of cancer to promiscuity, so women hide the fact that they have cervical cancer, it is an embarrassment to them. Therefore, it leads people to lack awareness of this cancer, compared to other cancers that are more commonly talked about.

During the focus groups, women and adolescent girls referenced sexually active women or women who have had multiple sex partners as one of the possible characteristics of women who develop cervical cancer. Prejudgments were observed in answers provided by other participants, where men mentioned *"promiscuity"* and pre-adolescent girls *"women who don´t respect themselves and sleep with men,"* and *"women who sell their bodies."*

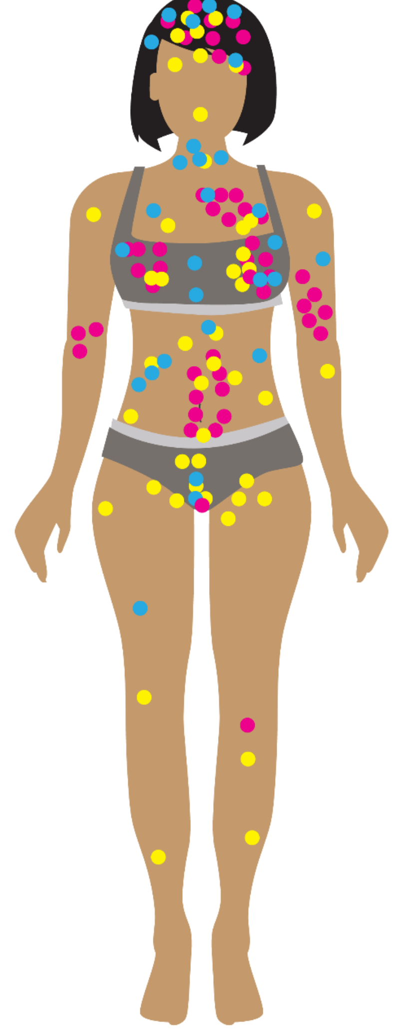
#9 - Girls know or have notion of gynecologic cancers

During the focus groups, girls had the opportunity to brainstorm and identify parts of the body or organs where cancer can develop by placing stickers in a female silhouette. In the following image, all stickers placed by the girls were integrated into a single silhouette where each color corresponds to a different group.

According to the image, and to what they expressed when reviewing the silhouette with them, cancer can develop in: the head, brain, eye, heart, throat, breast, stomach, vulva/vagina, ovaries, cervix, *"punky"*, liver, pancreas, intestine, bones, skin, hand, and legs. Breast cancer collected most of the stickers and was correctly mentioned in all the focus groups.

Adolescent girls from the private school were the most knowledgeable regarding female cancers because they have learned about some of them in their biology class. Many were able to name and talk about cervical and ovarian cancer.

The other girls (adolescent and pre-adolescent from public schools) seemed to have guessed that cancer happens in the "punky", vulva or vagina because after the research team provided additional information about cervical cancer, they were genuinely surprised that it could happen there.



- Pre-adolescent girls (Public School)
- Adolescent girls (Public School)
- Adolescent girls (Private School)

HPV Vaccine

#10 - HPV vaccination efforts have expanded to boys and adult population

Initially, the Ministry of Health launched the HPV vaccination program in schools (opt-in), specifically targeting pre-adolescent girls. A stakeholder from the ministry informed that the program then proceeded to include teenage girls and boys, and in some cases adults (until their 30s). Some private gynecologists have also provided it to cancer patients to help them with their treatment. Not all health care providers knew about the different groups that the Ministry of Health was targeting. The national vaccine schedule now includes the HPV vaccine for 11 to 15-year old's (not mandatory).

Confusion regarding age intervals and inclusion of boys for the HPV vaccine was observed among other participants. Women who had been offered the HPV vaccine were surprised and did not know that the vaccine was being offered at such an early age. Others did not understand why they were offering it to adult women when the vaccine is most effective when applied early. Parents, especially fathers, were taken aback when asked about providing the vaccine to boys. It was difficult for them to see the connection initially, when the vaccine is being strongly promoted to prevent cervical cancer. One father rejected the idea of providing it to his son.

#11 – There is no national campaign for HPV vaccination

There are no promotional activities or campaigns taking place to promote or inform about the HPV vaccine. Some health care providers expressed that it is being managed at a very low profile.

> *"... it's still like is a secret. So, you buy millions of dollars of vaccine, and you don´t have a national ongoing campaign. Sending a permission slip in a school for children to be vaccinated is not a national campaign. You need to meet with the PTA, you need to sell it to the parents, you need to sell it to the nurses, you need to sell it to the doctors, you need to sell it to the private Trinidad and Tobago medical...you need to sell it to us. Sell the product and the usefulness in saving lives against this dreadful disease called cancer."* (IDI – Healthcare provider 5)

A significant reduction of promotional materials and campaigns have been observed as compared to previous years. Information shared with parents at school when asking for their consent is minimal (see Annex).

#12 – Health personnel are not well informed about the HPV vaccine

One stakeholder expressed that health care personnel are being asked to promote a vaccine that they don´t know much about, and that they don´t believe in. There are many who don´t have correct information about the vaccine, even within the Ministry of Health, and are providing *"bad advice."* Furthermore, they have not been sensitized to eliminate misconceptions or prejudgments that individuals might have.

"I was wondering, why 26? And why somebody older shouldn´t get it [HPV vaccine]? *I think that is the policy of the Ministry of Health."* (IDI, Health Care Provider 3)

A 30-year-old woman who is also a mother has noted disagreement among health care providers. This has led her to feel even more insecure about giving consent for her daughter's vaccination.

"You will get one or couple of few points that it´s the best thing since sliced bread…then somebody else will be saying, a doctor will be saying -no, it may lead to this, it may lead to that-…" (FGD – Woman in her 30s)

#13 – There is not much involvement of the Ministry of Education

A stakeholder got the impression that the HPV vaccine did not get a strong buy-in from the Ministry of Education, even though the vaccine is being administered in schools. There are no individuals assigned to inform or answer parent´s questions or to sensitize school personnel (e.g., school principals, teachers). A member of the National Parent Teacher Association remembered participating in a meeting when the vaccine was first launched, but since then she had no longer heard of this issue.

#14 – "More" is the word, information is key

There is a great need from parents to have trustworthy information about the HPV vaccine. Most of the mothers and fathers who participated in the focus groups expressed that they don´t have enough information to provide consent. However, they are eager to learn about the vaccine and make the decision that is best for their child. Two main issues (lack of information and misinformation) are causing doubt, fear, mistrust and uncertainty among parents.

Lack of information has created misconceptions about the HPV vaccine and how it works. Parents believe that it is a new vaccine, that there is no knowledge about it (compared to the "old vaccines"), and that they are risking their child´s health when introducing this virus into their child´s body.

"The immunization is something new. It makes me feel as though I really don´t want to be a guinea pig, and after 20 years find out that there is some long-term effect. I want to be assured of how it works, how efficient it is." (FGD – Mother, Public School)

"As I understand how the vaccine works, it introduces a de-activated form of the virus, and that…yes you are telling me it is de-activated, but you are introducing this into my child´s system." (FGD - Woman in her 30s)

Many questions emerged during the focus groups with women, mothers and fathers that they want answered: Did they test it for a period of time with individuals to be sure it does not have long-term effects before being offered to the public? Who tested it? Who is it tested for? What is in the vaccine? Is it only for young girls? Older women? Is Trinidad and Tobago getting the real vaccine or the generic? What are the stats? Success rates? Is it effective? Is it really necessary? Does the vaccine last a lifetime? How long is it effective for? Is it mandatory? Do residual effects happen? Will it make them sterile? What are the pros and cons? What happens if a child gets the vaccine and she is

pregnant? If a child has a specific type of allergy, can she proceed with the vaccine? What are the trusted sources of information?

Parents who have wanted to know more about the HPV vaccine, have accessed online resources, such as private groups in Facebook, online chat rooms, and untrusted websites that have lead them to be exposed to misinformation, negative publicity, and antivaccination groups***.*** They have read stories of parents about alarming side-effects (e.g., down syndrome, paralysis, autism, blindness, auto-immune disease, death).

#15 – Side-effects are parent´s biggest concern

Concerns that parents have about the short and long-term side-effects of the HPV vaccine was identified as the main barrier for vaccine uptake in this study. Every mother and father talked and asked about them. Side-effects such as depression, hormonal imbalance, allergies, and reproductive difficulties are the most worrying to them.

"This [just] *came out, and all of the sudden you tell me to vaccinate my child, but then I don´t know if I do this and she has to go through depression, has to go through all sorts of things. I need to know more…I don´t think there is much information out there."* (FGD – Mother, Private School)

The concern that the HPV vaccine can encourage children to have sex or be promiscuous, was rarely mentioned during the focus groups with women and parents. Whereas, it was mentioned by stakeholders and health care providers. There did appear to be a belief among some parents that only those who are sexually active need the vaccine.

"…they came to school and spoke about it [HPV vaccine]*, and they shared briefly that it is to prevent cancer. She [daughter] asked me if she had to get it…and we told her this is for people who are having sex. Who has sex? Mommies, and daddies have sex. You have no husband, you are not having sex. She said -no mommy-, so then you don´t need it."*

#16 – Girls are willing to receive the vaccine, they do perceive the benefits

Girls are conscious about cancer and the importance of preventing it. They spoke naturally about some girls and boys having sex very early, or young girls getting pregnant. Therefore, they were able to understand the importance of the HPV vaccine. Many of them seemed excited after learning more about it, *"no woman wants to get cancer, I should go get my shots."* One girl from a private school who got the vaccine shared her experience and compared it to a normal shot: *"You have to get it like two or three times, and I got all of them…it felt like a vaccine."*

Teenage girls expressed interest in knowing more about the vaccine. Many mothers also agreed that it is important to consider the opinion of their daughters when deciding about this issue. Both groups agreed that an ideal moment to introduce this "talk" is when girls are starting to get their menstruation, since it is a time when very similar information is provided to them. Fathers were not fond of the idea of providing detailed information to their daughters about the vaccine or taking them into account when making this decision.

Recommendations

Provided by stakeholders:

- Communication. Promote vaccine as a cancer prevention vaccine, share history of the vaccine and success stories from other countries, present evidence. Give it a gender-based approach. Empower children, so that they can influence parents.
- Provide talking points to health care providers about the vaccine so that they are better equipped to answer questions. Oblige them to act professionally and not bring their *"personal views to the mix".*
- Campaign. Appeal to logic and emotions.
  - → Spokesperson: Cervical cancer survivors, provide testimonials (e.g., how she found out, how it impacted her life), female celebrity or the first lady, a young woman who got the vaccine and did not have side-effects and is leading a healthy life.
  - → Media channels: Social media (Facebook and others), TV, use free government airtime on TV.
- Change to opt-out approach. Focus on school-based delivery systems and create mechanism so that the second dose can be provided in school. Tie it in with the immunizations needed before STA/registration. Bundle it with other immunizations and create a schedule of visits to monitor pre-adolescents´ and adolescents´ health.
- Responsibilities. Government should be responsible for providing vaccines. NGOs should focus on awareness, sensitization, and advocacy; going to places with hard-to-reach populations (e.g., services in the evening, weekends, rural communities, migrants); partnering with the National Parents Teachers Association; conducting trainings to health care providers; implementing behavior change campaigns to support its implementation; and conduct research. Involve the private sector to improve access.

Provided by health care providers:

- Communication. Frame message in the context of cancer prevention, dissociate it from being a sexual transmitted infection (STI). Sell the idea of the vaccine to teachers, parents, nurses, doctors, etc. Sell the product, the usefulness (e.g., saving lives from cancer). *"Sell it!"*
- Promote credible sources of online information. Provide statistics.
- Campaign.
  - → Survival stories or personal accounts.
  - → Spokesperson: Male local artist (not a political figure), Minister of Health, young adult, cancer survivor. A young adult saying *"it's an injection to help me in my future, I have all these dreams. If I can prevent cancer before it starts…"*
  - → Media channels: Social media (Facebook, Instagram), the Ministry of Health should reach out through social media.
  - → Should be produced locally, so that people feel that the message is for them.
- Make the HPV vaccine mandatory, and part of the regular vaccine schedule. Leverage the last "top-up" vaccine (tetanus) at age 11 as an entry point for the HPV vaccine. Use it as a requirement to enroll in secondary school.
- Include and organize different delivery mechanisms (e.g., health centers, community centers, hospitals, schools), so that children not receiving normal schooling can be included. Teamwork.

Provided by women:

- Have representatives from the Ministry of Health inform parents about the HPV vaccine and answer their questions. Provide information that is age appropriate.
- Religious leaders should be approached in smaller communities, not at a high level.
- Conduct a campaign.
  - → Spokesperson: A real person (e.g., women, parent, girl, family physician who specializes in HPV). People who have had positive experiences, who had gotten the vaccine or who have been treated.
  - → Ideas for the campaign: "HPV not in me," "You want to protect your kids, here is the chance to do it again," or a basketball analogy like "Take the shot…" or "Put HPV on the spot, take the shot."
  - → Media channels: Radio, TV, social media (e.g., Facebook pages where "moms" talk, caravans).
- Partnership with other NGOs.

Provided by parents:

- Ministry of Health should provide information to parents in a way that people can ask questions (e.g., public forum, information sessions at different venues).
- Peer-teaching. Teens can learn from each other, but they must learn to be able to transfer the right information.
- Cervical cancer and HPV information should be integrated into sexual education.
- Conduct a campaign.
  - → They would trust testimonials.
  - → Spokesperson: Women who have gone through cervical cancer, true survivors that share their experience. This could help parents think about their daughters. They want to hear also from parents and children who already took the vaccine. Fathers gave the idea that celebrities can be used (e.g., reggae actors) to endorse the vaccine. Mothers were not attracted to this last idea.
  - → Media channels: Clinics, schools, and TV (morning shows). To reach teens, it should be through social media. They usually don´t respond well to information provided by parents.

Provided by girls:

- Organize talking opportunities with parents, so that they can ask questions and be more open to the information. like *"Sex-Ed"* for parents.
- The HPV vaccine should be provided between 10-18 years old. Children should receive information about this around the age when girls are getting their first menstruation.
- The HPV vaccine should be mandatory, a requirement for them to enter secondary school.
- Conduct a campaign.
  - → They like testimonials.
  - → Spokesperson: A young woman who had cervical cancer, a testimonial. They would like to hear her experience, what she went through.
  - → Media channels: TV, radio, news.

4Ps

Information included in the 4Ps of the **HPV vaccine** was obtained from the opinions expressed by women, mothers, fathers, and girls who participated in the focus groups. It is important to take into consideration that most of them lacked trustworthy information about the vaccine, that could have influenced their perceptions.

Product

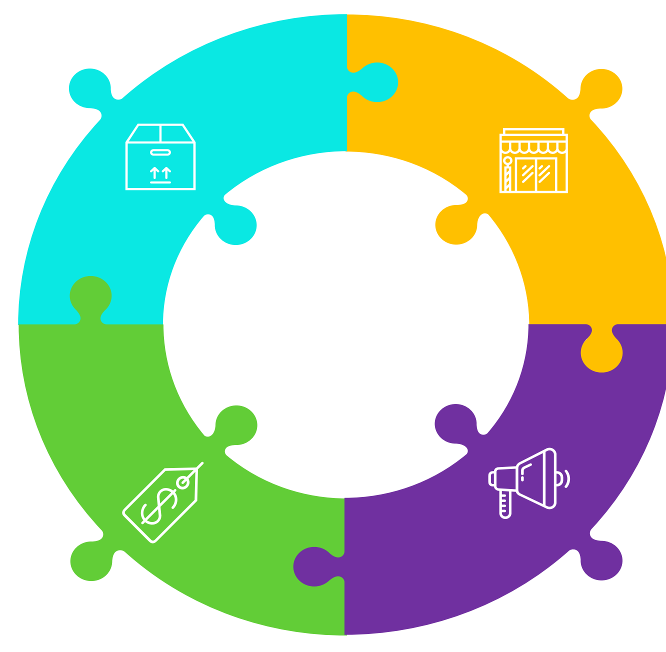
Benefits perceived: prevents cancer, it's free. No benefits were seen for boys, since it is a vaccine mainly promoted for girls.

Adults and parents mistrust the vaccine. Mothers and women are open to considering the vaccine for themselves or daughters/sons, if they are provided with more information. Their biggest concern are short and long-term side effects. Girls are motivated about the vaccine.

Place

The vaccine is currently being offered in schools (first dose), health centers/clinics, hospitals, and by private health providers. The second dose is not offered in schools, so parents need to take their children to the health center.

Women, parents and girls expressed their acceptability of these venues. Mothers did highlight their preference of being present during the application of the vaccine, that often happens when they go to the health clinics.



Price

The vaccine requires 2-3 doses. All doses are free in the public sector, and in the private sector the prices vary, but can start from $700 for the whole set of vaccines.

Parents seem to be held back by the cost of their child´s health that the vaccine could entail: hormonal imbalance, depression, allergies, reproductive difficulties, etc.

Promotion

Currently, the HPV vaccine is not being promoted actively. Limited information is being shared with some parents.

The best option to develop a campaign seems to be through testimonials of women who have suffered cervical cancer and women/children who have received the vaccine.

Target groups should be reached through: TV, radio, social media, clinics, schools and caravans.

Cervical Cancer Screening

#17 – There are no current efforts for cervical cancer screening uptake

There are no current efforts to increase cervical cancer screening, nothing to motivate the health system. The strategy is non-existent, and opportunistic. There is no clear national target, with some regions just trying to increase the screening numbers as much as possible and decrease late cancer diagnosis. Every region is responsible for the people who live in it.

There is a drive from the Ministry of Health to increase cervical screening, as part of the Inter-American Development Bank (IDB) project, at the end of this year. They must work together with the Cancer Society to identify the gaps and avoid working in the same areas.

A stakeholder also mentioned that a national screening program is going to be developed, and that the public and private sector will be invited to participate and be part of this effort to ensure geographical and socioeconomic equity.

#18 – Cervical cancer screening recommendations are not standardized

There are varying screening recommendations, clear guidelines are needed. Health personnel get confused about who needs to get screened, at what age should they start, how often should it be done, and where should it be conducted. A health care provided argued that the start age should be defined after looking at the sexual activity of the population in Trinidad and Tobago.

These varied recommendations could be heard when women were talking about pap smears. Some expressed that it should be done once a year, but others said that it depended on the results of the previous screenings or even the type of test.

> *"...It is stated that a pap smear should be done once a year, for three years. After three years they probably tell you, you can probably take a two-year break. So, you can skip one year, and you come the following year."* (FGD – Woman in her 30s)

#19 – Lack of personnel and screening kits affect pap smear uptake

Within the national health system, lack of trained personnel who can conduct pap smears and stock-outs of pap smear kits have been reported, even though most interviewees from the health sector said that they are widely available. A health care provider from the Ministry of Health shared that in the public system, all institutions and most health centers have pap smear kits. However, sometimes they have *"a bit of an issue of getting kits to the health centers."*

"…They don´t have kits at the clinic. If they do have them, there is only one doctor, so they might not be seen during that visit…The doctor can do about five in one day. If there are ten women, then they take the phone number of the woman and tell her to come back." (IDI – Health Care Provider 3)

In addition, several stakeholders and health care providers highlighted that to some women, specially working women, it is not easy to have access to screening services in the public sector due to the days assigned this type of service (once a week) and opening hours of the clinic (8:00 – 16:00 hrs.). There are only seven sites with evening clinics. Women who participated in the focus groups didn't mention this issue.

#20 – There is lack of awareness in women about the importance of screening

In general, stakeholders and health care providers agreed that the uptake of cervical cancer screening is low, *"not good."* They consider that many women are not aware of HPV, cervical cancer, screening procedures and the importance and benefits of periodic pap smears. There are cases were women come for their first pap smear after experiencing discomforts and they have *"full blown cancer."*

There are other women who dismiss the importance of the pap smear and fail to go periodically. Among them are women who think they don´t have a *"genetic"* predisposition, that believe they don´t have any risk factor, that lead a healthy lifestyle (e.g., good diet, exercise, medical check-ups except for pap smears) or that they don´t think is needed because they are not sexually active. A health care provider pointed out that young women in their 20s and postmenopausal women are the ones that worry her the most, since they are very dismissive about their need to have pap smears.

#21 – Fear, the most disabling in women

Fear was mentioned by all the target groups that participated in the study (i.e., stakeholders, health care providers, women of all age ranges) as one of the main barriers of having the pap smear. It was observed that fear is experienced differently, depending of the woman.

Women who have never had a pap smear are especially afraid of the process, they think that it's going to hurt. They don´t know what to expect. Their intention to have the pap smear, is sometimes hindered by other women´s stories who didn´t have a good experience with the doctor and/or procedure.

There are women who have had their pap smears before and understand the importance of it but fail to go periodically. They still fear and hate the process and may become very anxious when thinking about it.

"…I left about four years ago [the job that sent all employees for a full medical check-up, including a pap smear], *and since then I just haven´t done it* [pap smear]*, I hated it. I feel the pinch, I feel that pinch -chrrrick-, and I hear it. It messes me up!"* (FGD – Woman in her 40s)

Finally, there are women who fear the results. They fear what they might find, especially if they are having a problem. Some women prefer not to know and carry on with their daily routines and family responsibilities.

> *"...Depending on the lifestyle, that they have more than one sexual partner...a possibility could exist probably that they could develop cervical cancer or any sexual transmitted disease. So, they probably prefer not to know."* (FGD – Woman in her 30s)

Recommendations

Provided by stakeholders:

- Transition from a responsive to an active promotion of screening.
- Establish clear cervical cancer screening guidelines (e.g., who, where, how, how often, at what age).
- Train health care providers to reduce fears during screening and making patients feel comfortable.
- Continue to use mobile clinics (e.g., Cancer Society), and communicate schedule of mobile clinics through social media, and health centers.
- Government should engage with the private sector and emphasize screening through companies (e.g., healthy employees means less leave).
- Campaign.
  - → Spokesperson: Celebrity, women who were diagnosed with cervical cancer and want to share their positive story. Testimonies about people who did not do their pap smear and developed cancer.
  - → Media channels: Television, and social media (Facebook, Instagram, WhatsApp).
  - → Link to Mother´s Day (like Cancer Society), and provide service provision promotion during the month prior, *"no mother has to die from cancer."*
  - → Address fear of examination. Target men and male partners (for the prevention of HPV).
- Responsibilities. NGOs can work to increase awareness about cervical cancer as a highly preventable disease. They can have an advocacy role to monitor targets, coverage, and outreach. They can also reach women who normally don´t come forward (e.g., sex workers).

Provided by health care providers:

- Improve availability, offer screening services on weekends.
- Train nurses to do pap smears (task shifting), and all health professionals to be a pap smear advisor.
- Campaigns to raise cervical cancer awareness and promote pap smears.
  - → Messaging should focus on catching cancer before it starts and promoting personal responsibility: "Just because you´re alive, there are things you should be responsible for", *"Not only when cancer comes to your doorstep, you stand up and take notice."* Should pay special attention to women 40 years and older.
  - → Spokesperson: A busy woman. "Care about yourself," a busy woman comes in and then she just stops and looks at herself and says -I need to take care of myself, let me get my pap smear-."
  - → Pap smear month.

Provided by women:

- Communication. There is a need to de-mystify the female reproductive system and encourage women to know their bodies well (including their vagina). Women need to be empowered with information to ask questions and start conversations with their health care providers.

- It is necessary for teenage girls to start receiving the message that the pap smear is something that they will have to do. A participant gave an idea of having a point system that can incentivize women to do the test.

- Conduct a campaign.
  - → Testimonials. Women sharing their own experiences, with short clips that people can relate with.
  - → Spokesperson: Real people who have had the experience, who have suffered, who can share their experience after being diagnosed. They are the ones who can really sell it the best way.
  - → Ideas for the campaign: *"If you do a pap smear, you will be clear for another year," "Be sure, don´t be afraid to take a pap smear,"* or *"No fair, do the pap smear."*
  - → Promote a buddy-sister system, where friends can have appointments at the same time, so that they can keep track of each other.
  - → Media channels: Radio, social media (e.g., Facebook videos), posters, office spaces (or something that they can see every day).

- Production of videos that show the process of the pap smear (e.g., the duration, how women interact with their doctor).

Information included in the 4Ps of the **cervical cancer screening** was obtained from the opinions of women about the pap smear. There was not enough information to include other screening services.

Product

Benefits perceived: early detection, sense of ease (inner peace), provides confidence knowing you are OK, having knowledge about your health.

Negative aspects: it is an invasive procedure that cause women some challenges, metal applicator, and sometimes they distrust the swabbing technique.

Place

Pap smears are offered at primary health facilities, health centers, and by district nurses and health visitors. In health clinics, days and schedule is limited for the provision of this service.

Privately, it is offered in Family Planning Associations, Cancer Society and gynecologists.

Price

Pap smears are free in the public system but may require long waiting times and asking for permission from work to be able to go for their appointments.

In the private system, the prices may vary between $100 - $1000, depending on the provider and technique used. (e.g., slide pap smear, cytology, HPV test).

Having an abnormal pap smear could result in physical, economic, and emotional costs for them and their families.

Promotion

Currently, cervical cancer screening is not being actively promoted.

The best option to develop a campaign seems to be through testimonials of women who have suffered cervical cancer or had abnormal results. Providing messages that create awareness or empower women to and take control of their health.

Target groups should be reached through: TV, radio, social media, posters, office spaces, and news articles/reports.

Preventive Treatments

#22 – There is lack of knowledge about preventive treatments for cervical cancer

Stakeholders, some health care workers and women had little or no knowledge about preventive treatments for cervical cancer, types of treatments or places where they are done. Women in general associate this type of treatments with those provided to cancer patients (e.g., chemotherapy) or have a vague idea *"they scrape things inside of you."*

#23 – Delivery time of screening results is lengthy

Normally, in the private sector the screening results are provided 3-6 days after doing the pap smear. However, in the public sector it takes between 4-6 weeks. This is enough time for women to forget that they must come back for their results. Furthermore, there is no routine follow-up in the health system so that women can be contacted by phone, in case they don´t return, especially if their results are abnormal.

In some cases, results are not explained well to patients, causing confusion. Especially when they are inconclusive.

> *"…The doctor wasn´t the one to give me the results. The nurse called me from* [name excluded] *and they told me the results of the pap smear and that I had to come down immediately. I went in, they put me in a room, and they said -well, the results are inconclusive-. So, I asked what does that mean? -That just means that you might have cancer-."* (FGD – Woman in her 30s)

#24 – There is one colposcopy clinic servicing the entire region

When a woman gets an abnormal pap smear, they are sent to the colposcopy clinic. This clinic has a high number of referred patients, and the waiting list is long. Appointments can take between 6 to 12 weeks to happen. However, they do make sure to look at the referral letters to see if a patient has to be pulled up for immediate treatment.

CLOSING COMMENTS

The insights from this formative research study show that in Trinidad and Tobago, cervical cancer is less known than other female cancers (i.e., breast, ovarian) and often crowded by other NCDs. Its level of complexity poses a challenge to the population to understand the disease and the importance of establishing preventive behaviors that initiate at an early age and continue throughout life. It shows that it is not enough for the establishment of preventive behaviors to be aware of cervical cancer, its cause must be understood, how a sexually transmitted virus may or may not lead women and men to develop some type of cancer. Other cancers offer simpler explanations that are easier to grasp and accept, like genetic predisposition and environmental factors.

Cervical cancer preventive measures like the HPV vaccine, cervical cancer screening, and preventive treatments face barriers at different levels: 1) individual (i.e., lack of information, misconceptions, uncertainty, fear), 2) cultural (i.e., "good girl" image, sex related taboos, difficulty of women to put themselves first), and 3) structural barriers (i.e., absence of clear guidelines, uninformed health and educational staff, lack of supplies and qualified personnel, lack of follow-up system).

PSI-C now faces the important task of supporting the HPV vaccine and cervical cancer screening uptake. Therefore, to achieve a sustainable change over time, it is recommended to influence through different strategies the three levels where barriers were identified.

Individual Level

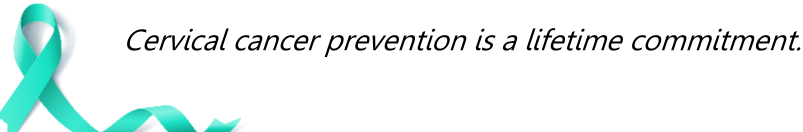
Increase knowledge and awareness of the general population about the HPV, cervical cancer, and preventive measures by providing clear and extensive information; facts; statistics; trustworthy sources; success stories of other countries; and testimonies from pre-adolescents/adolescents and women/men who have received the HPV vaccine, women who conduct periodic pap smears, and cervical cancer survivors. Consider the development of informational materials (e.g., leaflets), creation of online interactive spaces to inform and answer questions (e.g., website, Facebook page), and the development and implementation of campaign through different channels (e.g., mass and social media). Campaigns should be produced locally and aimed at providing a "human face" to cervical cancer, HPV and its prevention. Women, girls, and parents want to see real people and hear their experience, their testimonial. For example, girls who have been provided the HPV vaccine and (their parents), women who go to their pap smears, women who have been diagnosed with HPV, and young and older women who are cervical cancer survivors.

Cultural Level

Empower girls, young women, and mature women to express themselves, talk about their bodies, take care of their health and hold conversations with the health care providers. Inspire by exposing them to stories of real (powerful) girls and women, and cervical cancer survivors who have a story to tell. Also consider the development and implementation of a mass media and social campaign.

Structural level

Initiate communication and coordinate efforts with the Ministry of Health, Ministry of Education, NGOs, and the private sector. Consider supporting awareness and sensitizing efforts of health care providers and educational staff, the training on the delivery of the HPV vaccine and pap smears, and the massification of information to the population about the different public and private initiatives. Advocate the opt-out approach for the school-based delivery of the HPV vaccine and provision of the second vaccine in school grounds. Clarify policies, guidelines and targets for HPV vaccination and cervical cancer screening. Finally, share research findings that will inform national strategies.



ANNEX

Information brochure provided to parents

What is HPV ?

HPV is one of the most commonly transmitted STI and can be contracted through contact with infected skin. There are various types of HPV which affect the genital areas causing cervical cancer and genital warts.

What is Cervical Cancer ?

Cervical cancer is cancer in the cervix and occurs when the normal cells lining the cervix first gradually develop precancerous changes that turn into cancer to form a tumor.

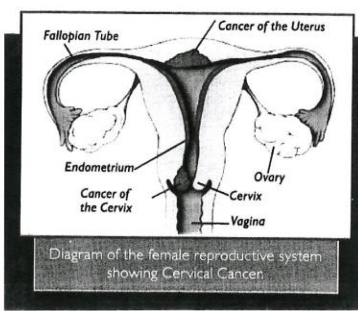


Diagram of the female reproductive system showing Cervical Cancer

How can we prevent it ?

By a **vaccine** that is used to help protect girls and women ages 9 through 26 against the following diseases caused by HPV:

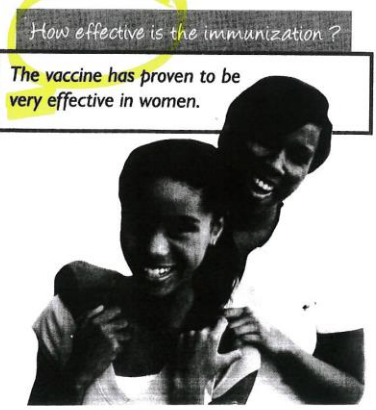
- Cervical cancer
- Vulvar and vaginal cancers
- Genital warts

How does it work ?

The vaccine stimulates the body to produce antibodies that protect against HPV.

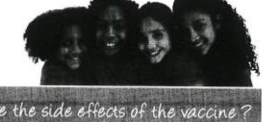
How effective is the immunization ?

The vaccine has proven to be very effective in women.



How long does protection last ?

The vaccine has long lasting protection



What are the side effects of the vaccine ?

Like any other vaccine, the most common side effects are:

- Mild pain, swelling, itching, burning, and redness at the injection site.

Other side effects may include:

- Headache
- Fever
- Nausea
- Dizziness
- Vomiting
- Fainting

If you experience any other reaction, immediately consult your health care provider.