FORMATIVE RESEARCH REPORT

AN ASSESSMENT OF THE READINESS FOR INTRODUCTION OF A CERVICAL CANCER VACCINE IN UGANDA

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ACRONYMS

AEFI	Adverse Events Following Immunisation
AOGU	Association of Obstetricians and Gynaecologists of Uganda
AUWD	Association of Uganda Women Doctors
BCG	Bacille Calmette Guerin
CAO	Chief Administrative Officer
CBO	Community Based Organization
CCT	Cold Chain Technician
CCV-	Cervical Cancer Vaccine
CDP	Child Days Plus
CHDC	Child Health and Development Centre
DDHS	Director of District Health Services
DHO	District Health Officer (formerly DDHS)
DHE	District Health Educator
EUA	Examination Under Anaesthesia
EPI	Expanded Programme for Immunization
EMIS	Education Management Information System
EPI	Expanded Program for Immunisation
FGD	Focus Group Discussion
GoU	Government of Uganda
GOP	Gynaecological Outpatient
GOPD	Gynaecological Outpatient Department
HC	Health Centre
HMIS	Health Management Information System
HPV	Human Papilloma Virus
HSSP	Health Sector Strategic Plan
HSD	Health Sub-district
IEC	Information, Education and Communication
IMR	Infant Mortality Rate
KI	Key Informant Interviews
LC	Local Council
LEEP	Loop Electrosurgical Excision Procedure
MCH	Maternal and child health
MMR	Maternal Mortality Rate/Ratio
MNT	Maternal Neonatal Tetanus
MoES	Ministry of Education and Sports
MoGLSD	Ministry of Gender, Labour and Social Development
MoH	Ministry of Health
NDA	National Drug Authority
NGO	Non Governmental Organization
NMS	National Medical Stores
NR	No Records
PHC	Primary Health Care
OPD	Out Patient Department
RDC	Resident District Commissioner

RH	Reproductive Health
PTA	Parent Teachers Association
PIASCY	Presidential Initiative on AIDS Strategy for Communicating to Young People
SHEP	School Health Project
STI	Sexually Transmitted Infection
SWOT	Strengths, Weaknesses, Opportunities and Threats (Analysis)
TT	Tetanus Toxoid
UNICEF	United Nations Children Fund
UNFPA	United Nations Fund for Population Activities [United Nations Population Fund]
UWESO	Uganda Women Effort to Save Orphans
UN	United Nations
UNCST	Uganda National Council for Science and Technology
UNEPI	Uganda National Expanded Program for Immunisation
UPE	Universal Primary Education
UAVI	Unaided Visual Inspection of cervix
VIA	Visual Inspection of Cervix with Acetic Acid
VHT	Village Health Team
WHO	World Health Organization
PATH	Program for Appropriate Technology in Health
CHDC	Child Health and Development Centre, (Makerere University)

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Executive Summary

This report is an outcome of a formative research carried out by Child Health and Development Centre, Faculty of Medicine, Makerere University in collaboration with Association of Obstetrics and Gynecologists of Uganda to inform the introduction of the HPV Vaccine (also referred to as the Cervical Cancer Vaccine) in Uganda. The study was funded by PATH.

The specific objectives of the study were to:-

1. Explore perceptions, understanding, knowledge and attitudes of primary and secondary decision makers regarding cervical cancer as a problem, its severity, vaccination/immunization and the cervical cancer vaccine.

2. Establish the nature of information needed by parents and by other influential community and national leaders and health professionals in order for them to make informed decisions and to give informed advice regarding the cervical cancer vaccine

3. Assess vaccine delivery system options for delivering the cervical cancer vaccine, including relevant structures, processes, and capacities available in the relevant ministries.

4. Review current health policies, the policy environment and processes relevant to policy formulation for vaccine introduction and adoption.

5. Develop a communication strategy and materials for different audiences to support a positive environment and positive individual attitudes to vaccine administration.

6. Develop an advocacy strategy to achieve awareness and support for cervical cancer prevention among policy-makers and key stakeholders at national and regional levels.

The research was designed as a cross sectional descriptive formative study, where qualitative research approaches were adopted to facilitate a broad in depth understanding of social cultural, vaccine delivery, policy and advocacy issues. The methodology adopted ensured triangulation of the approaches at the different phases of data collection and analysis for the different components, and ensured full and representative participation and integration of views and experiences of the different categories of study population. The study populations included: children aged 10 – 12 years, parents/guardians, head teachers/teachers, community leaders, health professionals, district and national political leaders.

The formative research found that in Uganda cervical cancer is the most common reproductive health malignancy in women - with a high burden and low survival rates. To date however the burden of disease is grossly underestimated in the face of low levels of knowledge even among the main frontline health professionals that are in contact with women daily. Furthermore the health system response to cervical cancer is limited.

Opportunistic rather than organized screening in done at a few facilities in Uganda and is constrained by lack of human resources and infrastructure.

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The glaring paucity in information on cervical cancer, its causes, risk factors, and the almost total lack of information on the Cervical Cancer Vaccine (HPV) among professionals who would be expected to be primary and secondary influencers for the Cervical Cancer Vaccine (HPV) efforts has important implications for the advocacy and communication strategy. Health professionals need to be targeted in order to equip them with the required information and skills to effectively support the Cervical Cancer Vaccine (HPV) and secondary prevention in general.

The research found that very little was known about cancer of the cervix. It was also evident that among lay people no distinction was made between cancer of the uterus and that of the cervix. The womb was perceived to be one organ. The lack of knowledge and understanding of cervical cancer seemed to be further propelled by the silence that seemed to surround cervical cancer as a problem. The majority of lay people did not know the symptoms of cancer of the cervix. Those who did associated similar symptoms with both cancer of the womb and that of the cervix namely: foul smelling vaginal discharge, sores or wounds that do not heal located inside the womb or on the opening to the womb and with continuous heavy vaginal bleeding. These symptoms however were also associated with STDs and with side effects of modern family planning methods and the majority of lay people expressed confusion regarding the symptoms. This confusion resulted in lay people not readily distinguish cancer of the cervix as a cancer.

The majority of lay people did not know that the Human Papiloma virus causes cervical cancer and that in the majority of cases it is sexually transmitted. Across all five districts there was a general perception that the cause was sexually related. This was evident in the risk factors highlighted across that included: promiscuity, multiple sexual partners, early sexual debut, sexually transmitted infections, poor personal hygiene, poor menstrual hygiene, and intercourse during menstruation, partner physical/sexual mismatch e.g. size, use of modern family planning methods especially pills, IUDs, injections. Other perceived risk factors included frequent deliveries, frequent abortions especially those that are unsafe, use of traditional herbs, eating certain foods e.g. oil distributed in IDP camps and poor diet.

The research found that most boys and girls aged 10 to 12 years had a good understanding of the benefits of vaccination/immunization, indicating that it was for disease prevention and protection, in particular against what they referred to as 'the 6 or 8' killer diseases. Among the adults who were comprised of parents/guardians, community leaders, teachers, and other key informants at district and national levels, there was general knowledge of the need for vaccination and the derived benefits of vaccination in terms of prevention of and protection against disease and in reduction of severity of diseases. Despite knowledge of the importance of vaccination and its benefits, some concerns were expressed regarding vaccination. The concerns mainly had to do with issues, such as safety of the vaccines, side effects, and the training and competence of health workers or vaccinators used. In districts such as Mbarara and Masaka it was reported that some private radio stations had run programmes de-campaigning vaccination programmes, parents reported that in the circumstances it took a lot of courage and counter-information to decide to take one's child for vaccination.

The research also found that declines in prevalence of some of the immunizable diseases observed by communities, has contributed to increased acceptance of immunization programs. This was mentioned by different categories of respondents. Diseases like measles and polio have reportedly showed the most significant declines. The results were reportedly obvious even to some community members who initially refused to have their children vaccinated.

Based on the known benefits of vaccination, most respondents were positive about the Cervical Cancer Vaccine (HPV). They however expressed a need for more information regarding cervical cancer as a problem, the vaccine itself, its safety, side effects, experiences and results from where the vaccine had been tried out and reasons why 10 -12 year old girls were targeted. They particularly wanted the Ministry of Health and health professionals' endorsement of the vaccine. They also had concerns on the long-term effects of the vaccine on the health and fertility of girls and indicated that they would like guarantees that it was not a new vaccine being tried out for the first time. They had fears that some politicians may use it for their own selfish reasons and some had suspicion that the government may be trying to use this as a way of controlling population growth especially in the north and northeast. In Kampala, where there have been vaccine trials in HIV that have failed, concern was expressed with regard to the use of children as guinea pigs. The acceptance of the Cervical Cancer (HPV) Vaccine therefore is likely to be dependent on the provision of accurate information and on the allaying of such fears through an effective communication and advocacy strategy.

The formative research explored who the primary and secondary decision makers would be with regard to vaccination of girls aged 10 to 12 years. The majority of respondents indicated that the primary decision makers were likely to be parents/guardians but most especially the mothers. However it was also pointed out that if the vaccination took place in school, the primary decision markers could be the school administrators other than parents. The research found that while in urban schools consent was normally sought from parents and their decisions respected, in rural schools once the health department agreed with the schools no consent was sought from parents. Parents were just informed of the planned vaccination program sometimes through their children or through the radio or the local council system. Children were then vaccinated at school. It was reported however that those parents who did not want their children vaccinated kept them at home on that day. There was also general recognition that children aged 10 to 12 years would have a role to play in deciding whether to be vaccinated or not. Parents acknowledged that children in this age group could accept or refuse to be vaccinated. Furthermore parents also acknowledged that while they have the final responsibility to consent to their children's vaccination the more important role would be to encourage and support their daughters to complete all three doses of the Cervical Cancer (HPV) Vaccine. Others perceived to be influential when it comes to vaccine introduction and acceptance included Church Leaders, Local Councils, Teachers, and Parliamentarians.

The research found no health services specifically designed for children aged 10-12 years although there were some existing strategies through which this particular age group was reached with specific health services. Most noteworthy among the strategies was the Child Days Plus. Others were different forms of outreaches that reached out to children both in schools and communities. There was general recognition that the majority of the target age

group are in school (75%) thus suggesting that a school based strategy would be an appropriate option with outreaches to reach girls out of school. An alternative strategy proposed was the delivery of the Cervical Cancer (HPV) Vaccine as a stand-alone project. While there was general acknowledgement that each of the proposed strategies has strengths and weaknesses, the majority of stakeholders argued that it would be cheaper and more cost effective if the vaccine was integrated into already ongoing programs rather than be introduced as a stand-alone. It was also argued that its integration into already existing strategies would in the long run ensure its sustainability.

Schools were perceived to be the most appropriate sites for vaccinating girls in this age group supplemented by outreach centers for vaccinating girls out of school. A major concern for the school administrators however was that when health workers used their schools for vaccinations they sometimes left used syringes, needles, and other supplies litter all over the compounds which puts the lives of the children at risk. Secondly they requested for joint planning with the health departments so that they could factor into their school calendars and programs the proposed vaccination days. There were complaints that sometimes health workers just turned up at schools without prior warning and planning. Finally concerns were expressed that while teachers were sometimes used to help with the vaccination process no allowances were paid to them for the extra work that they did. Both parents and teachers expressed concern about the fact that schools could not handle adverse effect that may occur after the vaccination. They argued that this being a new vaccine the after effects were not yet known. This is issue that should be carefully handled during the training. Failure to do so could cause serious credibility problems.

The research found both at national and district level that UNEPI has cold chain structures on the ground that can comfortably be used for the delivery of the Cervical Cancer (HPV) Vaccine to the targeted population throughout the country. It was however noted that in the event of rolling out, the storage at the national level would need be addressed and a cold chain assessment would need to be carried out in the areas designated for the roll out.

The research found interest among policy makers and implementers in undertaking HPV vaccination. It was viewed as a potentially longer-term solution to cervical cancer. Furthermore it was found that introducing the vaccine would not require a completely new policy, instead existing RH and EPI policies could be reviewed to address the overarching cervical cancer priorities such as screening and prevention. The findings strongly suggest that policy guidelines embodying national standards and capacities of Uganda to undertake this intervention will be needed. This would serve to inform the public at large on the need for vaccination against cervical cancer; which is currently not obvious given so little is known about it. There will also be need to prioritize the intervention and mainstream it into ongoing programs and provide legal and regulatory framework for implementation. The national standards should be based on best practices from immunization programs such as the Child Days Plus Strategy (CDPS) and routine outreach, which could be adapted to integrate HPV vaccination. This will introduce the intervention within a realistic framework of available resources and program priorities, adapting best practices to suit the existing resources and capacities.

The process of successful development and implementation of the vaccine initiative was considered to depend heavily upon the momentum and leadership from the national level in Ministry of Health and the district commitment to the program.

Planners at all levels underscored the need for commitment from government, both at the center and in districts to reflect in their budgets funds for effective logistics to support the vaccination program and the training and supervision of staff. Harmonized planning, level of funding, vaccine procurement and availability of skills were critical for program success. Regarding policy and program implementation, it was recommended that HPV vaccination be integrated in MoH annual work plans and the medium term expenditure framework. Both RH and EPI would develop policy guidelines with input from other stakeholders such as School Health Program and EPI.

Government and district ownership of the program was viewed, as a corner stone for sustainability and clear roles for different stakeholders were essential for harmonized implementation. Central to the success and sustainability of the intervention was the community acceptability of the vaccination as a safe and essential health intervention. Joint planning was recommended for central and district teams to ensure success of implementation.

1.0 INTRODUCTION

This report is an outcome of a formative research carried out by Child Health and Development Centre, Faculty of Medicine, Makerere University in collaboration with Association of Obstetrics and Gynecologists of Uganda to inform the introduction of the HPV Vaccine (also referred to as the Cervical Cancer Vaccine) in Uganda. The study was funded by PATH. The overall goal of PATH's Cervical Cancer Vaccine project was to strengthen the capacity of four developing countries including Uganda to prevent cervical cancer by generating and providing necessary evidence for decision making about public sector introduction of the cervical cancer vaccine.

1.1 Project Background

Cervical cancer has a devastating effect on women's lives worldwide. According to the most recent data, an estimated 466,000 new cases of cervical cancer occur among women worldwide each year, the vast majority of them in developing countries. Of the 231,000 women who die of cervical cancer annually approximately 80 percent are from developing countries, where cervical cancer is the most common cause of cancer deaths among women (Ferlay J et al 2002). Cervical cancer screening is a cost effective way to save lives. A World Bank study conducted in 1993 found that screening women every five years with standard follow up for identified cases cost about $100 per disability adjusted life year (DALY) gained compared with about $2600 per DALY for treatment of invasive cancer and palliative care (Jamison D.T, et al 1993). The regions hardest hit by cervical cancer are among the worlds' poorest. Central and South America, the Caribbean, sub Saharan Africa and parts of Asia are among those with the highest incidence rates-over 30 per 100,000 women. These rates compare with no more than 10 per 100,000 women in North America and Europe. Approximately 1.4 million women worldwide are living with cervical cancer (Ferlay J et al (2002). This estimate reflects the accumulation of new cases each year and the fact that few women in developing countries receive treatment.

An important reason for the higher incidence of cervical cancer in developing countries is the lack of effective screening programs to detect preconscious conditions and treat them before they progress to cancer. A 1985 estimate states that only about 5% of women in developing countries access cytology based opportunistic screening compared to over 50% in the developed world (WHO: 1985). If not detected and treated in a timely way, cervical cancer is nearly always fatal. In developing countries mortality rates are reported at 11.2 per 100,000 women on average, almost three times the rate of developed countries (Ferlay J et al (2002). Current estimates of cervical cancer incidence and death rates are probably lower than actual rates because many women with the disease do not receive medical care and therefore are not included in cancer registries. Limitations of diagnostic facilities and their tendency not to reach those in late stage illness, or those unable to pay for services, present further challenges to developing accurate estimates. In addition, the lack of organized health information systems makes recording the number of women with cervical cancer problematic (Alliance for Cervical Cancer Prevention (ACCP: 2004)

HPV is the primary cause of cervical cancer. Two HPV types —16 and 18, account for 70 percent of cases (though regional variations exist). In clinical trials, vaccines against HPV 16 and 18 are at least 95 percent effective in preventing persistent HPV infection and 100 percent effective in preventing type-specific cervical lesions. Combined with continued strengthening of simple, evidence-based screening and treatment approaches, effective cervical cancer vaccine programs could reduce developing-country cervical cancer deaths to the very low levels currently observed in many developed countries (ACCP: 2004).

Vaccines that protect against infection with the types of Human Papilloma Virus (HPV) commonly associated with cervical cancer (HPV 16 and 18) and genital warts (HPV 6 and 11) are now available. Because HPV vaccines are prophylactic, they must be administered prior to exposure to the virus, ideally during preadolescence or adolescence. The young age of the target vaccination population means that parents/guardians will most likely be the ones making the decisions as to whether their pre-adolescent children should be vaccinated against cervical cancer or not (ACCP: 2004).

Studies to date have demonstrated that these vaccines are safe and highly efficacious. Widespread acceptance of Cervical Cancer Vaccines (HPV) are likely to lend enormous health benefits by decreasing morbidity and mortality associated with cervical cancer and by reducing the psychosocial burden of both genital warts and abnormal Papanicolaou (Pap) test results. Savings in health care expenditures, including treatments for genital warts, pre-invasive cervical lesions, and cervical cancer would also be considerable (Zimet GD, et al 2000).

Despite this tremendous potential, many challenges need to be addressed. Innovative program strategies for delivering the vaccine to pre-adolescent girls—a population that has limited access to health services in most regions—must be tested. Accurate vaccine demand estimates are needed nationally, regionally, and globally. Vaccine manufacturers and international donors need to be engaged in developing solutions to vaccine supply challenges. And information on the soon-to-be-marketed vaccines and effective program strategies needs to be developed and broadly disseminated.

1.2 Cervical Cancer in Uganda

Although no accurate estimates of prevalence of cervical cancer are presently available in Uganda, existing literature suggests that overall prevalence is high. In a random sample of 960 women aged 15-59 years enrolled in a population based study in rural Uganda in 1999, the prevalence of HPV was found to be 16.7 percent and was highest among the younger women (Serwadda et al 1999). Hospital based studies indicate that cervical cancer is the most common malignancy among women in Uganda accounting for 40 percent of all genital tract cancers and for 8 percent of all malignancies (Mutyaba et al 2006 and Wabinga et al 2000). Of the women diagnosed with this cancer at Mulago hospital 80 percent present with advanced disease. These studies also observed that in some areas of the country there have been substantial increases in the incidence of cervical cancer.

Efforts to prevent and treat cervical cancer in Uganda have been hampered by poor access to screening facilities limited resources to scale up services and the lack of prevention

programs (Mutyaba et al 2006, Serwadda et al 1999). There are no organized cervical cancer screening programs in Uganda; the only available prevention strategy being opportunistic screening of women who come to health units for other medical reasons. Currently, pap smears are provided free at Mulago Hospital but not on a routine basis. This service is also provided on demand in some private antenatal, postnatal, gynecology, and family planning clinics.

Uganda was selected to participate in this project based on need, significance, ability, and political commitment. Need was defined by a high cervical cancer disease burden and low GNI per capita. Uganda also hosts a fairly large population size, enjoys a reasonable life expectancy (survival to age 60 for 15-year olds), and is considered to be representative of many other African countries in terms of infrastructure and health profile. Uganda also demonstrated infrastructure capacity for research and vaccine introduction activities and political commitment to cervical cancer prevention and to cervical cancer vaccine introduction.

1.3 Project Goal

The overall goal of the project in Uganda was to answer critical questions that would contribute to government decision-making and operational planning related to the introduction of the cervical cancer vaccine. This also includes a demonstration project.

1.3.1 Objectives

Specific objectives of the study were to: -

1. Explore perceptions, understanding, knowledge and attitudes of primary and secondary decision makers regarding cervical cancer as a problem, its severity, vaccination/immunization and the cervical cancer vaccine.

2. Establish the nature of information needed by parents and by other influential community and national leaders and health professionals in order for them to make informed decisions and to give informed advice regarding the cervical cancer vaccine

3. Assess vaccine delivery system options for delivering the cervical cancer vaccine, including relevant structures, processes, and capacities available in the relevant ministries.

4. Review current health policies, the policy environment and processes relevant to policy formulation for vaccine introduction and adoption.

5. Develop a communication strategy and materials for different audiences to support a positive environment and positive individual attitudes to vaccine administration.

6. Develop an advocacy strategy to achieve awareness and support for cervical cancer prevention among policy-makers and key stakeholders at national and regional levels.

This research had three interrelated research components involving social cultural, vaccine delivery and policy related issues. The social cultural component explored the perceptions of pre-adolescents regarding common health problems that they face, whom they discuss these problems with, their sources of information on health issues and their preferred sources and modes of communication. The study also explored the perceptions, understandings, knowledge and attitudes of parents/guardians and of influential community, religious and national leaders and health professionals regarding cervical cancer as a problem and its severity, vaccination/immunization, vaccine delivery options currently available and their perceptions regarding the introduction of a cervical cancer prevention vaccine. Furthermore the study explored the nature of information needed by parents and by other influential community and national leaders and health professionals in order for them to make informed decisions and to give informed advice regarding the cervical cancer vaccine.

The vaccine delivery component collected and analyzed data on vaccine delivery system options in Uganda, including relevant structures, processes, and capacities in the Ministry of Health. It also identified needs specific to Cervical Cancer Vaccine (HPV) and examined the suitability of existing institutional structures (e.g., schools, primary health services) for delivering the HPV vaccine to pre-adolescents in communities. The perceptions of key stakeholders regarding the capacity for these institutional structures to deliver the HPV vaccine and the impact that the introduction of the vaccine is likely to have on selected services and staff were also explored.

The policy component reviewed the relevant health policy environment, mapping key stakeholders in the decision making processes and identifying critical issues important to national decision making about cervical cancer prevention services including vaccine adoption. The study assessed present policies and processes of their formulation that are relevant in the introduction of a cervical cancer vaccine. Furthermore it established and mapped out the key stakeholders and 'champions' driving the key policies relevant to cervical cancer and identified critical issues that will inform, leverage and support cervical cancer vaccine introduction plans in the country.

2.0 METHODOLOGY

2.1 Study design

This study was designed as a cross sectional descriptive formative study, where qualitative research approaches were adopted to facilitate a broad in depth understanding of social cultural, vaccine delivery, policy and advocacy issues for the introduction of a cervical cancer vaccine. The methodology adopted ensured triangulation of the approaches at the different phases of data collection and analysis for the different components, and ensured full and representative participation and integration of views and experiences of the different categories of study population.

2.2 Study Sites

The study districts were selected from the four major regions of the country and included; Gulu in the North, Soroti in the East, Mbarara in the West and Masaka in the Central region. Kampala district was included because of its multi-ethnicity and cosmopolitan nature. The selection criteria for the study sites included regional and socio-cultural variations, major language groupings, differences in vaccination experiences, prevalence of cervical cancer as recorded in the Uganda cancer registry, and the existence of regional referral hospitals in the area where information on cervical cancer, screening and treatment services could be accessed.

2.3 Study Populations

The study populations included: children aged 10 – 12 years, parents/guardians, head teachers/teachers, community leaders, health professionals, district and national political leaders.

Girls in and out of school aged 10-12 years are the primary target population for the cervical cancer vaccine. They were considered to be important sources of information relating to who normally makes decisions regarding their health, their main sources of health information and their preferred sources and modes of communication when it comes to health related issues. Boys in this age group were also included in the study. Although they will not be vaccinated they are the future parents and their knowledge and attitudes can influence vaccine acceptance among the girls.

Parents/guardians were considered to be the primary decision makers on issues related to health and vaccination for children. Their knowledge, understanding, experience and attitudes regarding cervical cancer, its severity and vaccination are likely to influence their acceptance of the vaccine.

School Management Committees/Teachers/head teachers are likely to be influential in the decision making process in families and since schools are possible sites for vaccine delivery their knowledge, understanding, experience and attitudes regarding cervical cancer and vaccination are likely to influence vaccine acceptance among the primary decision makers.

Community/opinion leaders are also likely to influence the decision-making processes in the community, including enforcement of regulations. They participate in community mobilization for immunization of children, and are involved in logistics for vaccine delivery and monitoring. Their knowledge, understanding, experience and attitudes regarding cervical cancer and vaccination are likely to influence vaccine acceptance among the primary decision makers.

District political and religious leaders influence the decision-making processes in the community, including enforcement of regulations, participation in community mobilization and advocacy for immunization of children. Their knowledge, understanding, experience and attitudes regarding cervical cancer and vaccination are likely to influence the introduction and acceptance of the vaccine.

National political and cultural leaders influence decision-making processes at national level and sway public opinions on issues such as immunization.

Health professionals including heath service providers are likely to be knowledgeable about the burden of cervical cancer, prevention and treatment services available. Their knowledge, understanding, experience and attitudes regarding cervical cancer and vaccination are likely to influence vaccine acceptance among the primary decision makers.

Managers of District Health Service including the District Director of Health Services (DDHS), District Nursing Officer/ Immunization Officer, Drug Inspector and Hospital Directors. This category is directly involved in implementation of health policies, guidelines, programs and management of service delivery. Their experiences with the implementation of different health policies and programs and their views/ assessment of the feasibility and mechanism of introducing a new vaccine may inform the process of decision making and policy formulation for cervical cancer project.

National political leaders including members of parliament, ministers influence decision-making processes at national level, including advocacy for vaccine introduction, policy formulation and legislation.

Stakeholders from relevant Government Ministries and departments such Ministry of education, Ministry of Gender and development partners such as WHO UNICEF, UNFPA. These are stakeholders and actors in formulation of health policies including those relating to children, vaccines and immunization. In addition they implement policies, fund and or support health programs meant for young adolescents.

2.4 Sampling Methodology

With the exception of the girls aged 10 – 12 years in schools who were randomly selected, all the other respondents including out of school girls of the same age, were purposively selected basing on their knowledge, experience, and understanding of issues relating to cervical cancer, vaccine delivery, policy initiation and formulation or based on their social positions that rendered them potentially influential in society.

The sampling of girls and boys aged 10 – 12 years in school was conducted with the help of teachers. In consultation with the district education officers, two schools were purposively selected in each district. While in two of the districts the selection of the two schools was based on the rural /urban dimension, in the other three districts the selection was based on the public /private dimension and within each of these schools the gender dimension was observed.

Within communities Local Council officials at LC one level guided the research team in identifying and organizing children who where out of school, while in selecting parents of children of the same age group, school administrators helped the researchers in identifying parents who had children in this age group. In districts where schools were not able to invite parents, mobilizers who were Local Council officials were used in organizing the parents with children 10-12 years in the communities for focus group discussions as well as in identifying girls out of school.

2.5 Data collection methods

The study used several data collection methods. These included: Key informant interviews; Focus Group Discussions; Desk Reviews; Observations and a One-day Workshop. The specific data collection methods used by the different components and numbers interviewed by category are summarized in Tables 2.1 – 2.3.

Table 2.1: Data collection methods of different components

Component	Desk Review	Key Informant interviews	Focus Group Discussions	Observations and Workshop
Burden of Disease	X	X		
Social Cultural		X	X	
Vaccine Delivery	X	X	X	X
Policy	X	X		

Table 2.2: Respondents and numbers of Focus Group Discussions conducted with each

Respondents	Number of Focus Group Discussions
Children aged 10-12/boys and girls in and out of school	25
Parents/Guardians	21
Opinion Leaders	9
Teachers	11
School Management Committees	5
Total	71

Table 2.3: Respondents and numbers of Key Informants Interviewed

Respondents	Number of Interviews
LC5, Opinion leaders, officials from health and education	40
Cold Chain technicians EPI Focal Persons	11
Gynecologists, Medical officers, Midwives in public/private practice	19
National Program Managers, Development Partners, Prof. Associations, Advocacy Groups, Medical Bureaus	37

Data on the burden of disease were collected from records in five referral hospitals in Gulu, Soroti, Masaka, Mbarara and Kampala. Records reviewed included the Out Patient (OPD) register, inpatient/admission registers, theatre register and Gynaecological OPD register where this existed.

Focus Group Discussions were conducted with children both boys and girls in schools aged 10 – 12 years, and girls of the same age group out of schools, teachers, parents and community leader (religious, cultural and political). The main aim of the focus group

discussions was to ensure that the diversity of opinions, knowledge, experiences and practices were captured. Key informant interviews using open-ended topic guides were conducted with health professionals, politicians, cultural leaders and other national and international stakeholders.

For both in-depth interviews and Focus Group Discussions, the researchers asked for permission from the respondents to tape record the discussions, which were later on transcribed, translated and typed.

The table below summarizes the total numbers of Key informant interviews and Focus Group Discussions that were conducted at national level and in each of the districts during the course of the study.

Table 2.4: Summary of the study design Population and data collected

Population	Selection criterion	Sampling procedure	Data Collection method	Data collected
Boys and girls aged 10-12 years both in and out of school	- Primary target population for the cervical cancer vaccine	- In school random (male/female) - Out of school snow balling (Rural/urban)	- FGDs	-10 FGDs in school 5 FGDs for out of school
Teachers	Senior woman/man, science teachers and head teachers	Purposive (rural/urban)	FGDs	10 FGDs
Parents	Primary decision makers on issues relating to health and vaccination of children.	Purposive through the PTA (rural/urban) Male/female	FGDs	20 FGDs
Community leaders	Influence decision making, enforcement of regulations, community mobilization for vaccine delivery and monitoring.	Purposive (urban/rural) cultural, religious, political	FGDs	5 FGDs
Health service & technical managers - DHO - Med sup - Dist Nursing officer - Educ. Officers - NGOs e.g	District managers with influence on policy and implementation of vaccine programs	Purposive	KIs	25KIs

UWESO				
District - political LC chairpersons – Secretary for social services,	- Role in policy initiation and implementation - Advocacy	Purposive	KIs	10 KIs
Health service providers: - Med. Officers - Nurse/Midwife Ob/gyn Private med pract./private midwives	Knowledge on cervical cancer, experience with vaccine delivery,	Purposive	KIs	30KIs
National political leaders: - Chairperson of social services committee, - Women parliamentarians, - Youth MPs	Influence policy decision making and advocacy.	purposive	KIs	3KIs
Development & National stakeholders: UNICEF WHO, UNFPA AOGU AUWD UNMA Cervical cancer survivors association chairperson	Involved in funding and advocacy for women and children's health	Purposive	KIs	21KIs

2.6 Data Management and Analysis

2.6.1 Data Entry and Analysis

After the data collection process, the FGDs were transcribed fully in vernacular prior to being translated into English. The transcribed FGDs and interviews were word-processed. The core team members read through and reviewed all the FGDs and interviews identifying key themes and sub-themes in order to construct coding schemes. In order to manage this large data set, the teams adopted a team based approach to data analysis using Atlas Ti version 5.0 computer assisted qualitative data analysis software to facilitate the management and analysis of this data. Texts were coded and clustered along themes and sub-themes for

subsequent analysis. Key phrases or statements made on any of the topics or emerging themes were quoted and integrated into the report.

On the basis of the coding schemes that were developed, the research team proceeded to apply the codes to represent the themes, patterns and categories. Each Team proceeded with the analysis and synthesis of information. The process involved: reading and reflecting, interacting with the literature and data and commenting on it, extracting from the codes, quotes to be used when writing up, linking similar ideas from transcripts, identifying contradictions in arguments, comparing dissimilarities in transcripts, building arguments with links to supporting evidence in the data. Both entered data and the raw data from the field will be stored in a safe place in both hard and soft copy for a period of 5 years before destruction.

2.6.2 Quality Assurance

Before the actual data collection commenced, data collection instruments were pre-tested. The findings were utilized to refine the instruments. The pilot testing of instruments was conducted during the training in a district, which was outside the selected 5 study districts. This enabled the interviewers to gain first hand experience on how to administer the instruments in the community and understand how data was to be analyzed. During data collection an effective supervision system was put in place to ensure that errors were minimized. The principal and co-investigators supported the research assistants to conduct the interviews and focus group discussions in order to ensure that quality data was collected. The study teams crosschecked, edited and reviewed all data at the end of each fieldwork day.

2.6.3 Ethical Consideration

Permission was sought from the National Council for Science and Technology (UNCST) as required of all research projects done in Uganda. Prior to the submission of this proposal to the National Council for Science and Technology for ethical and national clearance it was submitted to CHDC Protocol Review Committee for approval. The Research Committee at the Child Health and Development Centre (CHDC) took overall responsibility for ensuring that the research adheres to international ethical standards. In the districts, clearance was sought from relevant district political and administrative authorities such as the LC IV Chairman, Resident District Commissioner (RDC), Chief Administrative Officer (CAO), District Director of Health Services (DDHS), and local leaders in the study communities. The purpose of the study was explained to all the parties as a scientific study whose results would increase scientific knowledge and understanding of cervical cancer prevention in Uganda and elsewhere. This study involved boys and girls aged 10 to 12 years as research respondents. Being minors' special protection was accorded to them following the guidelines stipulated by National Council for Science and Technology (UNCST). Consent for the children's participation in the study was sought from their parents/guardians and the assent of the children was also sought.

FINDINGS

3.0. BURDEN OF DISEASE

3.1 INTRODUCTION

The formative research sought to determine the burden of disease of cervical cancer in five districts of Uganda and the current state of preventive and treatment services for cervical cancer. Cancer of the cervix uteri is the second most common cancer among women worldwide, with an estimated 468 000 new cases and 233 000 deaths in the year 2000. Almost 80% of the cases occur in developing countries, where, in many regions, this is the most common cancer among women(Parkin et al. 2003).

In Uganda the age-standardized incidence rate (ASR) was 40.7 per 100,000 women. Trend data showed that there has been an increase in the ASR from 19.7 in the 1960's to 40.7 per 100,000 in 1994-1997(Wabinga et al. 2000). Despite data collection and reporting limitations, data from two other cancer registries in Uganda (Mbarara (1997-2000) and West Nile (1961-1978) both showed that cervical cancer was the most common malignancy among women in Mbarara and the 2nd most common in West Nile.(Parkin, Ferlay, Hamdi-Cherif, Sitas, Thomas, Wabinga, & Whelan 2003)

3.1.1 Risk factors for cervical cancer

Some studies done in Uganda that document risk factors associated with cervical cancer show that early age at first sex and high parity are associated with increased risk for cervical cancer. Other risk factors studied include low social class, poor hygiene and HPV infection.(Newton et al. 2004)(Blossom et al. 2007).

The association between HIV and invasive cancer is complex and not well understood(Orem, Othieno, & Remick 2004). Although cervical cancer has been considered an "AIDS defining illness, this association has not been observed in some of the studies in Uganda. In a case control study of 116 women with invasive cervical cancer and 116 hospital controls the odds of being HIV- infected was not significantly higher. However HIV infected and invasive cervical cancer patients were more likely to be younger than HIV-negative invasive cervical cancer group. But younger HIV infected women were more likely to present with HIV and invasive cervical cancer.(Sekirime & Gray 2007) did not show a significant increased risk of HIV infection

3.1.2 Cancer survival

Cervical cancer survival studies in Uganda are based on data from Kyaddondo cancer registry. They show very low survival rates. The relative 3-year survival rate was 52% (Wabinga et al. 2003) and the 5 year survival rate was less than 20%.(Gondos et al. 2005). Most women report with very late stage disease that can only be managed by radiotherapy. However, many women may not be eligible for chemoradiotherapy due to anatomical changes resulting from late stage disease (McArdle & Kigula-Mugambe 2007).

Most data reviewed on the burden of disease was obtained from cancer registries. There was paucity of data from the hospitals and health units that offer services to cervical cancer patients. Overall, the records reviewed had a number of shortcomings namely: Data on cervical cancer is not routinely captured by the Health Management Information System (HMIS); Data are kept in multiple service based registers making it difficult to track cervical cancer patients' information; Data were not recorded in a uniformly agreed manner at all the hospital; Data were most often incomplete and the Most vital data that could be used in determining the magnitude of cervical cancer are missing

3.2 Burden of cervical cancer

Other than data from the national cancer registry, no national data specific to RH cancers existed at the time of the study so the actual magnitude of cervical cancer is unknown. Based on the National Cancer registry for Kyaddondo County, Kampala district cervical cancer is the commonest RH cancer accounting for 40% of all cancers and 80% of female genital cancers. Breast cancer accounts for 23% and all other cancers 37%. Until 1998, the Department of Pathology was the only one-histopathology laboratory that processed and reported on all biopsy specimens. With more histopathology laboratories in the country, the database may be incomplete.

Clinical data from the other hospitals were inaccurate and had missing data. However all hospitals reported that they saw late stage cervical cancer patients; Gynecologists at all hospitals reported seeing at least 2 cases a week (table 1). Mulago and Lacor hospital in Gulu offered Radiotherapy treatment. More than two-thirds of Gynecological deaths were of cervical cancer patients. Five of the 9 hospitals included in the study could offer cervical cancer preventive services; all hospitals could offer surgery for cervical cancer and only 3 could offer cryosurgery. While LEEP was functional in Mulago the LEEP equipment at Masaka Hospital was faulty. Mulago Hospital consistently performed Examination under anesthesia and over 70% of patients had late stage disease ≥ stage 3(see Appendix).

Table 3.1: Cervical cancer case load by anecdotal reports from Key informants

Respondent	Kampala	Masaka		Mbarara		Gulu		Soroti
	Mulago Hospital	Masaka Hospital	Kitovu Hospital	MUST	MMH	Gulu Hospital	Lacor Hospital	Soroti Hospital
Med Sup						2 per week on ward		
Ob/Gyn	24 in last 3 months		12 in 6 months	4 per week.	2 in last 3 months	2 new cases per month.	NR	10 cases per week
Midwife Government	103 in GOPD in past year	DR		3 per week		DR	NR	5 per month
Midwife Private	0	0		0		0		6 per month
Medical officer private	1 in last 3 months	2 in last 1 month		0		0		0

3.3 Cervical Cancer Case management at -Mulago National Referral Hospital

Mulago National Referral Hospital is the main referral hospital for cervical cancer management and palliative care. Table 2 presents data from Mulago and Nsambya hospital, a private-not-for profit hospital in Kampala. Clinical reports for 2006 indicate 30% bed occupancy on the Gynecological wards by cervical cancer patients of whom 80% were diagnosed with late stage disease and could benefit from radiotherapy offered in Mulago. Furthermore 35% (484/1400) of patients seen in the gynecology out patients had suspected cervical cancer.

The 2007 hospital records reviewed revealed that patients with cervical cancer had 63.5% bed occupancy indicating an increase. Deaths due to cervical cancer of the total gynecological deaths were at 70%. Investigative surgery for cervical cancer formed 40% of the theatre workload. The majority of patients diagnosed had stage III/IV disease classified as late stage disease (72%). This underscores the high burden that appears to be on the increase. Regarding the age distribution of the patients most were between 41-50 years (40%). Noteworthy is the fact that 20% of patients seen were between 31-40years. There were also a number of patients above 70 years, which is not typical. This data is important if one is to plan an intervention with limited resources.

3.4 Cervical cancer case load Mulago vs. Nsambya Hospital

Nsambya hospital was visited during the pre-testing of data collection tools for the main research. It is a faith-based hospital located just outside of the city center and therefore easily accessible. On average throughout the year bed occupancy by cervical cancer patients was at 20% with a range of 0 - 62.5%. In terms of workload Nsambya Hospital performs more major gyne operations [surgery for early cervical cancer] with only a small percentage (9.3) of the workload being investigative surgery for cervical cancer. This is probably due to its capacity to screen and catch most of the pre-cancers in the operable stage. The research did not capture the proportion of this that might have been modern treatment methods [Cryotherapy and LEEP] for early stage cervical cancer.

Table 3.2 Cervical cancer caseload for Mulago and Nsambya hospitals

	Mulago	Nsambya
Suspected cervical cancer in GOP*	484	-
Cases admitted to Gynaecological ward *	430	38
% bed occupancy by cervical cancer	63.5	20*
EUA for cervical cancer*	195(40%)	24(9.3%)
Total gyne operations*	494	224
Major gyne surgery for cervical cancer*	1	3
Transfers to radiotherapy department	103	4
Deaths from cervical cancer*	26(6%)	3(8%)

* Figures computed for over one year prior to research

3.5 Cervical cancer prevention and management in the health sector

The Uganda national health infrastructure plan has adopted a system with seven levels of health service delivery from Health centre 1-4, district, regional, and national referral (HSSP). Referral usually starts from the lowest of health units. To date, cervical cancer screening and diagnosis is not done at health centers I-4. In addition the 2006 revised service standards for RH regarding RH cancers recommend the following: No more unaided visual inspection in the community and the introduction of colposcopy in general hospitals and regional referral hospitals. However gynecologists who usually perform this investigation are not deployed in general hospitals. Histopathology is supposed to remain at the regional referral hospitals but none of the referral hospitals visited during the study had histopathologists. Cervical cancer staging and surgery is now supposed to be done in the general hospitals. This will require support supervision by gynecologists at the regional referral hospitals. Palliative care is now advocated for at all levels of healthcare but radiotherapy still remains the sole function of Mulago National Referral Hospital. Findings from the five districts suggest that the 2006

revised service standards for RH regarding RH cancers recommendations do not match the realities in the districts and may therefore be difficult to implement.

The records review revealed that the basic requirements for cervical cancer screening and diagnosis were available in all the public hospitals. Screening when done however was only opportunistic rather than systematic because of constraints such as inadequate equipment and personnel. In the private hospitals i.e. Lacor (Gulu), Kitovu (Masaka) and Mayanja Memorial (Mbarara) the responses indicated no service provision for prevention or diagnosis of cervical cancer and there were hardly any surgeries carried out for early stage disease in most of the hospitals. Furthermore disease stage could not be determined in most hospitals since it was not indicated in the theatre registers reviewed. Surgery was the mainstay of treatment for early stage disease outside Kampala district where modern methods e.g. Cryotherapy, conization and LEEP are conspicuously absent. Masaka was the only district where LEEP existed but the equipment was nonfunctional.

None of the hospitals had capacity for HPV detection. This reflects similar findings from the ECSA countries' situation analysis concerning cervical cancer conducted in 2005. Among the main highlights of this study were: Basic requirements for cervical cancer screening were available in all hospitals; Inadequate cervical cancer screening; Treatment facilities for pre-cancer were inadequate at all levels; Shortage of staff i.e. gynecologists, cytotechnicians and histopathologists and Record keeping very poor[4]

3.6 Health worker knowledge and perception on cervical cancer

In-depth interviews were held with 24 health workers from government and private health units that explored their perceptions on cervical cancer as a health problem and the health sector response to cervical cancer.

3.6.1: Knowledge on Cervical Cancer

All the midwives interviewed perceived cervical cancer as a serious health problem. The most common response regarding its severity was presentation with late stage disease that has a poor prognosis. They had basic knowledge of risk factors for cervical cancer to include multiple sexual partners, high parity and age respectively. Midwives however were not confident about what they knew about cervical cancer because they were not commonly exposed to cervical cancer patients.

> *"I don't know how the patient presents but the doctors are the ones who see such patients" [Midwife government hospital]*

Private midwives seemed less knowledgeable than hospital based midwives few private midwives could mention age, age at sexual debut, or multiple sexual partners. None mentioned HPV infection. Some midwives mentioned myths or had inaccurate information about cervical cancer risk. The age bracket of the women affected was reported as over 40 years apart from the midwife in Mulago who had seen younger women with cervical cancer i.e. at 25 years. This list was not exhaustive since the medically proven risk factors for this disease include; having sex at an early age, multiple sexual partners, sexual partners who have

multiple partners or are in high risk sexual activities, long-term use of birth control pills (more than 5 years), Weakened immune system.

The midwives interviewed also could not distinguish methods for cancer screening from cervical cancer staging and management. They thought that direct visual inspection of the cervix with acetic acid is used in making a diagnosis of cervical cancer and not to identify cervical pre-cancerous lesions. All the midwives were not conversant with modern treatment methods for early stage cervical cancer including Cryotherapy and loop electrosurgical procedure [LEEP].

Although medical officers interviewed admitted to rarely seeing Gynecological patients, they perceived cervical cancer as a serious health problem. Half the respondents mentioned HIV and STIs as a risk to cervical cancer. Medical officers also held the myth that abortion is a risk factor for cervical cancer. Half of them stated direct visual inspection of cervix for detection of pre-cancerous cervical lesions, but their understanding of the age of target population and the protocol for detection and treatment of pre-cancer was limited.

All gynecologists reported that cervical cancer is a serious health problem with the main issues being late presentation, high prevalence, young age at presentation and low awareness amongst health personnel and the public. Although all mentioned common risk factors, most did not mention that HPV and HIV might be associated with precancerous cervical lesions. This underscores the need for this cadre to be updated on the current scientific facts regarding cervical cancer so they can become appropriate resource persons in disseminating information and offering services to the communities they serve.

These findings highlight the knowledge gap among frontline health providers who are a good resource for screen and refer women with pre-cancerous lesions for expect care and management.

3.6.2 Perceptions regarding the health sector response to cervical cancer

On the heath sector response to cervical cancer prevention, Midwives observed that while health education and integrated reproductive health services reach the lower health units they did not have a specific focus on cervical cancer. Midwives from Masaka mentioned the impact of preventive services, given their experience in participating in a cervical cancer-screening program, and those from Soroti noted inadequate community mobilization for the Pap smear program that had only recently started. Others felt government response was poor in that it was only involved in management of late stage disease.

> *"There is no policy, no advocacy, and no posters" in other words nothing was being done [private midwife, Gulu].*

More than half of the gynecologist stated that there was no health sector response in other words there are no programs dedicated to cervical cancer prevention and management. Districts had the capacity to diagnose and treat cervical cancer but did not have adequate

facilities to do so. (Capacity was perceived in the context of being able to at least do a speculum vaginal examination for gross abnormalities on the cervix, examination under anaesthesia to obtain a biopsy specimen, stage the disease, and limited surgery for operable invasive disease).

> *"We have no capacity. All are referred to Mulago Hospital for management" [Medical officer in Private practice]*

> *"Capacity is mainly concentrated at the regional referral centers…No equipment even basic things like speculums, pap smear kits…we have no cytologists"[Gynecologist])*

Most hospitals lacked capacity to screen and treat cervical pre-cancerous lesions. Mulago Hospital's capacity to diagnose cervical cancer was in part due to its proximity to the Department of Pathology that processed and reported the biopsies and its dual role as a national teaching hospital. All regional referral hospitals (except Mbarara hospital) sent their specimens to the Department of Pathology. In addition the department of radiotherapy at Mulago hospital offered palliative treatment for advanced disease.

The research found that opportunistic rather than organized screening is practiced due to lack of resources or commitment to develop a national screening program. There are a few trained cytopathologists in the country who are overwhelmed with reporting on Pap smears sent to them. No training program exists or is planned for cytopathologists.

A number of missed opportunities for cervical cancer screening exist and have not been exploited. Maternal and child health clinics mainly attend to children. Cervical cancer screening could be introduced for mothers who bring children for immunization. Postnatal care service should also implement routine cervical cancer screening. At the time of the research, HMIS did not collect any information on malignancy. Recent revision of the HMIS data collection tools has now included monthly reporting of common malignancies from all hospitals but is still silent on cervical cancer screening.

3.7 Training and Information Needs

All health workers interviewed did not have adequate knowledge about the association between HPV and cervical cancer. All except one gynecologist knew about the Cervical Cancer (HPV)Vaccine and wanted more information about the HPV vaccine. Majority of them especially the doctors wanted to know the results of the phase III trials and all information pertaining to safety and efficacy of the vaccine. With this paucity in information on cervical cancer, its causes, risk factors, and the almost total lack of information on the HPV vaccine among professionals who would be expected to be primary and secondary influencers for HPV vaccine efforts, its important that focus be made on training this important group of people on these issue. All pre- service training curricula for health workers and Continuing Medical Education sessions should include cervical cancer prevention, screening, and management

The formative research found that in Uganda cervical cancer is the most common reproductive health malignancy in women - with a high burden and low survival rates. To date however the burden of disease is grossly underestimated in the face of low levels of

knowledge even among the main frontline health professionals that are in contact with women daily. Furthermore the health system response to cervical cancer is limited. Opportunistic rather than organized screening in done at a few facilities in Uganda and is constrained by lack of human resources and infrastructure.

The glaring paucity in information on cervical cancer, its causes, risk factors, and the almost total lack of information on the Cervical Cancer Vaccine (HPV) among professionals who would be expected to be primary and secondary influencers for the Cervical Cancer Vaccine (HPV) efforts has important implications for the advocacy and communication strategy. Health professionals need to be targeted in order to equip them with the required information and skills to effectively support the Cervical Cancer Vaccine (HPV) and secondary prevention in general.

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4.0 SOCIAL CULTURAL COMPONENT

4.1 Introduction

This chapter presents the findings from the social cultural component of the formative research. Data was collected from a cross section of the general public including young people and adults and from both males and females on their; perceptions, understanding, knowledge and attitudes regarding cervical cancer as a problem, vaccination/immunization, the cervical cancer vaccine. Furthermore the research sought to establish the nature of information needed by the various stakeholders in order to make informed decisions and to give informed advice regarding the cervical cancer vaccine

Prior to the main data collection, an exploratory study was conducted that explored broadly people's knowledge and understanding of cervical cancer as well terminologies and phraseologies used to describe cervical cancer, the parts of the body that it affects and its associated conditions. The main purpose was to establish acceptable terminologies and phrases used that were both age and gender appropriate and socially and culturally acceptable. The exploratory study was predicated on the assumption that there was insufficient information and understanding of cervical cancer as a problem within the general public. It was also assumed that cervical cancer being a condition affecting women's sexual and reproductive health was likely to be shrouded in silence, as were most other sexual and reproductive health problems that affect women. Furthermore it was acknowledged that women's sexual and reproductive health problems are socially and culturally perceived to be private, and were in most cases not discussed openly in public spheres. Consequently little was known about the terminologies and phraseologies used in discussing such conditions; yet the research team needed this information in order to proceed with the design of the research tools for the main study.

The exploratory study formed the basis for the main data collection. It helped clarify for the research team, people's understanding of cervical cancer, its social and cultural constructs and its perceived causes, signs and symptoms. It also provided a set of terminologies and phrases that were socially and culturally acceptable across gender and age that were used in the development of the research tools.

4.2 Perceptions and Knowledge about cervical cancer

As a start during the exploratory study women, traditional healers, traditional birth attendants and health workers in private and government units were all asked based on their experience what the common reproductive health problems were that were experienced by women in their communities. With the exception of health workers, most of the other respondents described these reproductive health problems faced not by name but by the symptoms that they presented. It was evident from their responses that most sexually transmitted infections were perceived to present similar symptoms, and there were in most

cases no clear differentiations made between them. Those specifically mentioned by name were syphilis and gonorrhea.

The research also found a lot of commonalities in the reproductive health problems reported to be common among women across the five districts. These included: swellings, cysts or growths in the uterus, pseudo and ectopic pregnancies, wounds or boils in and around the uterus, vaginal discharges of different types ranging from plain watery discharges to whitish discharges that looked like cuddled milk, to thick yellowish discharges that were associated with a foul smell and pus. Also mentioned were a range of diseases and conditions that affect the fallopian tubes including blockage, and pain in and around the fallopian tubes, abortions and miscarriages, severe abdominal pain, prolapsed uterus, unusual heat in the uterus, abnormal vaginal bleeding, including during pregnancy, after delivery and after menopause, cancer of the uterus, infertility, incomplete placenta evacuation, blockage of the birth canal, genital itching, and warts.

Cancer of the uterus was mentioned as one of the common reproductive health problems but no mention was made of cancer of the cervix. With the exception of the health professionals most other lay people did not make the distinction between cancer of the uterus and cancer of the cervix. It was explained that the diagnosis of cancer of the uterus was usually made in health units after a proper examination by a trained health professional. According to the traditional healers it was only when symptoms became severe and patients did not respond to treatment that they suspected that it might be cancer and when the patient eventually died this served as confirmation that they were suffering from cancer because one of its known characteristics was that it is terminal.

4.2.1 Knowledge of Cancer

The research found that the term *'cancer'* has been adopted as part of the vocabulary in the local languages. It was written and pronounced as '*Kansa'* in Luganda, Runyankore and Luo and as *'Ekansa'* in Ateso. In addition however there were other local terminologies used to refer to cancer. In Luganda it was referred to as *'Kokoolo'* in Runyankore *'Ekokooro'* and in Luo two terms were used '*Lugaga'* and *'two Rubanga.'* '*Lugaga'* literally means *'poison in the body that does not heal'* and *'two Rubanga* "literally means '*God's disease'*. It was explained that *"Two Rubanga*" was commonly used to refer to conditions or diseases whose origin was not known and that have no cure. It was further explained that the adopted use of the term *'cancer'* in the local languages had to do with the failure to find appropriate terminology that suited lay people's understanding of cancer. In Masaka the traditional healers reported that lay people have problems differentiating between cancer and witchcraft.

The majority of children reported that they knew or had heard about cancer from a variety of sources but also through personal encounters with cancer patients. There were variations in knowledge and understanding of cancer between children in the urban and rural schools and between those in and out of school. In Mbarara for example among the boys who participated in a focus group discussion ten out of the eleven in the urban school had heard about cancer, while only three out of eleven in the rural school had heard about it. Children who knew about cancer or had heard about it knew it as a serious condition, which doctors could not cure and which resulted in death. The children likened it to AIDS, saying it had no cure and was fatal as illustrated by the following quotes from the discussions:

Once you suffer from cancer you can never be cured
It is a killer disease
It kills many people, it has no cure, doctors cannot treat it, and it spreads at a high rate.
It kills when not treated at an early stage.

Cancer was also described by children as a disease that causes destruction to body organs as illustrated by these quotes:

"It causes destruction to the lungs;
it destroys the intestines,
it destroys the brain".

The majority of children were aware that cancer could affect different parts of the body:

"It affects the lungs,
it affects the bones,
it affects blood,
it affects the legs,

The cancers most commonly mentioned by the children were cancer of the breast and cancer of the lungs. They specifically associated lung cancer with smoking as illustrated by these quotes from the discussions,

"When you smoke you get cancer of the lungs",
"*Cancer can spoil your lungs and you easily die,*

It was evident during the discussions that most of what the children knew about cancer was based on hearsay

"*I heard people talking about it,*
I heard that it affects women's breasts and this causes a woman's breasts to be cut off,
"I heard from our parish priest that cancer could affect our stomachs".
"I heard that when you do not eat regularly you suffer from cancer,"

While some children mentioned that they had learnt about cancer in class others reported that they knew of neighbors and relatives who had suffered and died as a result of cancer as illustrated by the following quotes.

"Our neighbor had cancer, they cut off her breast
"Our family friend, had cancer of the lungs she did not get proper medical care and she died".
It attacked my grandfather and he died
"Cancer attacked my uncle. It attacked his arms. He was a school director and could no longer work. So they took him to the village. Eventually they called us on phone to inform us about his death".

While the majority of children were aware that cancer affected both men and women the majority could not differentiate between cancers that affect only women from those that affect both men and women. Girls more than the boys were aware of cancers that affect only women, although nearly all children In the districts of Gulu, Mbarara and Kampala mentioned cancer of the breast but only girls mentioned cancer of the uterus. They explained that:

"It affects the womb and, the sores do not heal … (FGD, Girls in School, Gulu)

In Mbarara they explained that:

"*Cancer of the womb affects that part of the body where the baby grows"*

Girls also mentioned that they had heard or knew cases of women who suffered from cancer.

"A woman was suffering from cancer of the womb and she spent a long time suffering, when she went to the hospital they removed her wombs"

"I have heard that when one is suffering from breast cancer all her breasts get swollen and eventually they die".

"My aunt had breast cancer and she died".

"There is a woman who used to smoke a lot and she got breast cancer. I saw her; she used to live with us".

Girls out of school were however less knowledgeable about cancer. Many who initially said that they knew cancer turned out to only know the word '*cancer',* and could not explain it further. Others however gave examples of people whom they perceived to have had cancer but the descriptions given were somewhat confusing as illustrated in the following quotations:

> *"My father was traveling to Nyendo when he had an accident. Broken glasses entered his cheek. He became sick and up to now his cheek is still swollen. When he went to the hospital - they told him it was cancer"*

> *"I heard about a child. She was going to fetch firewood she fell down and a thorn pricked her. She was taken to the health centre and was given an injection and the doctor told her she has cancer but she got healed"*

> *"There are times when an insect intrudes into a person's eye without her knowing what the foreign body is. But when she goes to the hospital she may be told that her eye needs to be removed because it has cancer".*

Girls out of school in Gulu also associated cancer with witchcraft within the family:

> *"I saw a certain lady at our home, who used to sell in a shop…her knee started swelling and they advised her to go to hospital, she kept saying they had bewitched her because of jealousy about her business. She had it for three years…the area started rotting and they kept telling her to go to hospital, but because they said she had been bewitched by her in-law's co-wife, they took her to hospital and they cut off her leg because they said she had cancer"*

Children knew about cancer perceived it to be a serious condition that has no cure and that eventually resulted in death. The majority were aware that cancer affects both men and women, although many were not able to differentiate between cancers that affect men and those that affect women. Most commonly mentioned were breast and lung cancer. The majority of children also knew that cancer of the lungs was caused by smoking, and were aware that cancer can affect different parts of the body. It was evident however that most of what the children knew about cancer was based on hearsay although others reported that they had learnt about it in class.

Discussions with community leaders, parents/guardians, teachers and other adults across all five districts revealed that they were aware about cancer in general. They knew it as a condition that affects different parts of the body including the *blood, legs, lungs, breasts and throat.* Many gave examples of people whom they knew or had heard about who had suffered from these different types of cancers that included men, women and children. Cancer was also perceived by the majority to be a severe condition, incurable and often life threatening.

In discussing different cancers the only distinction made in terms of terminology was that they were referred to as cancer of whatever part of the body they affected. For example people talked about cancer of the breast, cancer of the lungs, cancer of the throat, cancer of the womb and so on. The majority of lay people reported that only professionally trained health workers in health units or hospitals diagnosed cancer as cancer. As previously mentioned traditional healers reported that when patients came to them for treatment and they gave them herbs and they failed to get better they usually suspected that they might have cancer so they referred them to the hospitals where they could get a proper diagnosis.

While the majority of the adult respondents explained that they had first hand experience with cancers others explained that they had only heard about cancers from health workers, radio programmes or had read about them in newspapers.

"We get to know about cancer from patients who are in hospitals, some of whom happen to be our own relatives,
Our friends and workmates also informs us
Sometimes we get to know about cancer because a relative is suffering from it.
We often get information about cancer from radio health programs, which are run by health workers.
We also read about types of cancer from newspapers particularly in the health columns which are written by health workers" (FGD, Male parents, Soroti)

It was evident from the discussions across all five districts that the majority of lay people knew cancer as a serious condition that was also in most cases fatal. In discussing the cancers that they had heard or knew about Women in Mbarara mentioned that:

"*There is a type of cancer that causes breasts to fall off…*
There is also another type of cancer, which shreds the intestines….
"There is that one which destroys the throat so much so that the patients can hardly swallow anything…The throat becomes inflamed causing the patients failure to eat or drink and this results in death in the long run."

Unlike the children the majority of adults differentiated between cancers that affect men and those that affect only women. The two most commonly mentioned cancers that affect women were cancer of the breast and cancer of the womb. Examples were given of women whom they knew who had suffered and died of breast cancer. A woman leader in Kampala observed however that:

"Of all these cancers, it seems the cancer of the breast has been given a lot of attention and so many women have been talking about it, thus a lot of sensitization has been conducted on breast cancer, the same should be done for other cancers as well. What we know is that if a cancer is operated, then it develops fast bringing death nearer than could be"(Woman Leader, Kampala).

Both children and adults knew cancer as a serious condition that affected different parts of the body. Cancer was also known to be a condition that could not be treated and in most cases resulted in death. It was known to affect both men and women. Breast cancer was the most common cancer mentioned as affecting only women, while cancer of the cervix was hardly mentioned raising the question of why cancer of the cervix, which claims more lives among women, was not mentioned.

4.2.2 Knowledge and understanding of cervical cancer

The research found that very little was known about cervical cancer by the general population even among health workers the condition was reportedly not well known or understood. Among lay people cancer of the cervix was not mentioned spontaneously during the discussions but when the researchers mentioned some of its symptoms some respondents indicated that they recognized them and that they had heard or knew of cases in their communities.

The terminologies and phases used to refer to cancer of the cervix in all the five districts were based mainly on the symptoms presented by cervical cancer patients. The terminologies and phrases used in most cases overlapped with those used to refer to other genital tract diseases and this was part of the confusion underlying their inability to differentiate cancer of the cervix from STDs and in some cases complications arising from the use of modern family planning methods. In all four local languages there was no specific terminology used to describe the internal female genitalia. In Runyankore they were referred to as '*ebicweka byomubiri ebyekihama*" and in Luganda *"ebitundu ebyekyama*" the literal translation in English is 'parts of the body that are private or secret'. Also mentioned in Luganda was *"wansi"* which literally means 'down there'.

In each of the four languages however there was specific terminology and phases used to refer to the uterus. The terms *"aliget'* in Ateso, '*nyinenda'* in Runyankore, '*ot nywal*' in Luo and '*nabaana'* in Luganda were all widely understood to refer to the uterus/womb. It was evident from the discussions that the womb was understood to be one organ; in other words no distinction was made between the uterus and it's opening which is the cervix. Consequently no distinction was made by lay people between cancer of the uterus and cancer of the cervix, to them it was the same. Similarly the research found that the terminology used by lay people to describe both cancer of the cervix and cancer of the uterus was the same. In Luganda it was referred to as '*Kansa waa nabaana'* or '*kokoolo waa nabaana'*, in Runyankore it was referred to as '*ekokooro yanyinenda" or 'Kansa yanyinenda'*. In Ateso "*Ekansa la awuresi*" was used to

describe not only cancer of the uterus but also cancer of the cervix and of the ovaries. In Luo it was referred to as *Kansa me ot nywal*' which is cancer of the womb.

However it was also evident from the discussions and interviews that health professionals have tried to help lay people understand that there is a difference between cancer of the womb and that of the cervix. When explaining the diagnosis of cervical cancer, they had coined a terminology in the local languages that literally translated to "*cancer of the/opening/ mouth/ door/or entrance to the womb.* In Luo '*dog ot nywal*' or '*dog ot nyodo'* were used to describe the opening of the uterus. Health professionals referred to cervical cancer as '*kansa/ two me dog ot nywal*' cancer of the mouth or opening of the womb. '*Ot nywal*" literally means 'house of birth' also referred to as '*ot nyodo'. 'Dog ot nywal*' (mouth of the womb*)* refers to the cervix. According to the health workers in Gulu, no local terminologies aptly described cervical cancer, but '*dog ot nywal* or *dog ot nyodo*', was coined to describe cancer of the cervix. In Runyankore cancer of the cervix was translated by health personnel to '*Ekokoolo yo omura' or 'ekokoolo yo'omunwa gwa nyinenda' or ' Kansa yo'omunwa gwa nyinenda'*, which literally translates to ' cancer of the mouth of the womb'. In Luganda it was referred to as '*Kansa wa kumumwa gwanabaana'* or '*kokoolo wa kumumwa gwanabaana'* again when literally translated it referred to cancer of the mouth of the womb. This was the terminology adopted and used in the instruments for the main data collection. What was interesting however was that the majority of lay people did not readily recognize the terminology coined by the health professionals to refer to cervical cancer.

In the main study a question was asked to nearly all respondents with the exception of children of "*have you heard about cervical cancer* "to which half of the respondents answered yes, however when asked the question that followed which was "*what have you heard about it*", very few indeed could say anything more. This suggested that very little was known. The responses given included:

We mostly know about cancer of the uterus and cancer of the breasts that disturbs women a lot.
We have not heard about cervical cancer".

Cancer of the cervix also attacks the uterus and both of these have the same symptoms. The patient gets pain in the tubes when the cancer has grown but when it is still in infancy there are no symptoms and one cannot know that they have it".

It affects women and their uteruses have to be removed"
"That it is a problem that affects mainly older women"
"That a woman can go for a check up and if it is found it can be removed"
"It is the same as cancer of the uterus"(Female parents in Mbarara)

In Masaka female parents made the following remarks:

"Cancer of the cervix? We thought it was the same as that of the uterus. In both cases the uterus is affected…
I had never realized there was a difference between cancer of the cervix and that of the part near to the back. I only know that there is cancer of the uterus"
" What I know about that one is that a woman who suffers from it may have periods on and off and at the wrong times. Such a woman bleeds at the wrong times. They get a discharge with blood when they play sex with their husbands. It may be thought that such a person has cancer of the uterus".

One of the male parents in Soroti reported that:

"My mother died of it…she used to bleed in an abnormal way and she also used to get a discharge. I was told by one of my older siblings…. I was not able to find out how long she had cancer but she had it for some time and she did not tell anyone about her condition".

Another male parent also in Soroti remarked:

"Those are conditions which women do not divulge they will only talk when they are badly off sometimes they will not even say what the problem is when they need money to go for treatment so they explain it as if it is some other problem that is why it is difficult to know more about such conditions"

In Mbarara male parents explained that:

"We get to know about it, especially when women suffer severe bleeding... currently everyone associates severed bleeding in older women, with cancer"

"People used to believe that cervical cancer was hereditary: passed on from grandparents to children then to grandchildren"

" What I heard was that cervical cancer is such a horrifying medical condition that it takes blood relations to take care of the patient because sometimes the patient has a foul smell"

It was evident from the interviews and discussions that very little was known about cancer of the cervix. It was also evident that among lay people no distinction was made between cancer of the uterus and that of the cervix. The womb was perceived to be one organ. Even with the distinction made by health workers for the lay people between cancer of the womb and cancer of the opening of the womb it remained not well understood. The implications are that both the communication strategies and IEC materials need to address this gap in knowledge and understanding of cancer of the cervix. Lay people will need to understand the problem that the Cervical Cancer (HPV) Vaccine is meant to prevent.

4.3 Perceived signs and symptoms of cervical cancer

The research found that lay people associated cancer of the womb and cervical cancer with three major symptoms namely; foul smelling vaginal discharge, sores or wounds that do not heal located inside the womb or on the opening to the womb and with continuous heavy vaginal bleeding Different terminologies and phrases were used to explain these symptoms. The foul smelling vaginal discharge was referred to as *"Ecwilili"* in Ateso, which literally means continuous watery vaginal discharge that usually requires a woman to heavily pad herself in addition to wrapping herself in a lot of clothing to conceal the discharge and smell. In Luo two phrases were used to describe it '*Aibuk ne ebosit', which* refers to a foul watery vaginal discharge and '*Abulon'*, which refers to a pus discharge.

Other perceived symptoms mentioned were sores or wounds in the womb or on the opening of the womb. In Ateso they were referred to as '*Edola la awuresi'* which literally

means a wound on the opening of the womb that doesn't heal and '*Ajimi na awuresi'*, which just means a wound on the opening of the womb. Traditional healers in Gulu used the term '*bur 'to* refer to these wounds or sores that did not heal. They referred to '*bur iic'* (wounds in the stomach), or '*bur me ic'* (wounds of the stomach). *'Bur ma kane'* wounds or sores that hide, in the stomach. Others include '*bur ma pe cang i ot me nyodo'* or*, 'bur ma bedo i dog ot nyodo'* (wounds in the womb or, at the opening to the womb that do not heal). Also mentioned by traditional birth attendants was '*two ma lota lota' that* refers to sickness that causes growths, while '*akwota'* are swellings or growths. The term '*adola'* was used for describing chronic wounds or ulcers. In both Gulu and Soroti wounds on the cervix or in the womb that do not heal were perceived to be cancerous, the operational phrase being 'wounds that do not heal'.

In Mbarara mention was made of abnormal bleeding that was continuous as asymptom of cancer of the cervix. They referred to it as '*ekyejweiso'*, which refers to a condition of non-stop continuous heavy vaginal bleeding. This is the same terminology that is used in the local Bible translation to describe the woman with the issue of blood. In Ateso '*Aibuk awokot*,' was used to refer to a similar condition of continuous vaginal bleeding. Here the operational phrase non-stop or continuous vaginal bleeding. In Gulu the term '*two remo'* – blood disease or disease of blood, was used. Another term '*Lutugu,'* was used to refer to prolonged vaginal bleeding often heavy in nature. The prolonged vaginal bleeding even after menopause was mentioned as a symptom of cancer of the womb/cervix.

There were cases where these symptoms were described as being sequential as illustrated by this quote from an FGD with women in Kampala

Women with cancer of the womb s*tart with the sores in the womb, later the start bleeding after sexual intercourse the bleeding then continues and later turns into a smelly vaginal discharge".*

While in other cases the symptoms were described as occurring separately and as being unrelated. It was evident however that these symptoms were confused and or mixed up with those of other STIs such as Syphilis. In explaining the symptoms of cancer of the cervix women in Mbarara included the following: vaginal bleeding (*ekyejwiso*), foul vaginal discharge (*ekinuuko kyamahira*), painful intercourse (*okushasha waba noyeterana nomusheija*) and lower abdominal pain (*okushasha enda nto*), they also mentioned *eshundo (*genital warts) and *ekiho* (*c*andida). Other symptoms mentioned were:

"Women fail to conceive and later they are diagnosed with cervical cancer"

" Others keep feeling persistent abdominal pains"

" Other women complain of pain in their private parts and they discharge a foul smelling fluid;

" Some women experience excruciating pain during sexual intercourse; similarly, such cases usually end up being diagnosed as cervical cancer".

"Others first suffered from very small swellings in their private parts which caused continual pain".

"I know of a woman whose womb got swollen, after a medical check up she was diagnosed with cervical cancer. Yet, others complain of terminal heat in their wombs".

" Some women hear rumbling in their uteruses and they can hardly tell"

"The common symptoms by which people can know that they have cancer are: being in agony yet not being able to establish what one is suffering from; severe headaches and various allergies".

Across all five districts several of the respondents also associated c*andidiasis* and other STIs with cervical cancer. They explained that STIs and cervical cancer seemed to have similar symptoms except that those of cancer were more severe.

"They say that even this disease which they call candidiasis also brings out that smelly discharge. Now what's the difference between that candidiasis and cervical cancer? Because somebody can be mistaken between those two diseases because most of those STD diseases cause that smelly discharge so we are just a bit confused about that disease"(FGD, Female parent, Mbarara)

A male parent observed that:

"I have heard of cancer that attacks women's private parts. The symptoms are such that the person is like she has got herpes in her private parts. Initially she gets a rash and she looks like a spider has attacked her, the skin forms another layer and then the herpes burst. I think this is what is called cancer of the private parts among women. The Baganda call it 'embaluuka'(FGD, Male parent, Masaka)

Furthermore, it was also evident from the discussions with mainly the female respondents that there was also some confusion between symptoms of cervical cancer and what they perceived as side effects of using modern family planning methods. Female respondents across the five districts shared these concerns:

"When some women use family planning injections and the coil the bleeding on and on and on others stop completely, while others bleed very heavily. Now what is the difference between that bleeding and that of cancer is not the same is it not coming from the same place"(FGD, Female Parents, Kampala)

The majority of lay people did not know the symptoms of cancer of the cervix. Those who did associated similar symptoms with both cancer of the womb and that of the cervix namely: foul smelling vaginal discharge, sores or wounds that do not heal located inside the womb or on the opening to the womb and with continuous heavy vaginal bleeding. These symptoms however were also associated with STDs and with side effects of modern family planning methods and the majority of lay people expressed confusion regarding the symptoms. This confusion resulted in lay people not readily distinguish cancer of the cervix as a cancer.

This is another area that the communication strategies and IEC materials will need to address. The symptoms of cervical cancer need to be clearly distinguished for the lay people from those of other STIs, and from side effects of modern family planning if for no other reason than that cancer of the cervix does result in death if it is not diagnosed early

4.4 Perceived Causes of Cervical Cancer

The research found that the cause of cervical cancer was generally unknown to most people, but given that cervical cancer itself was also largely unknown this was hardly surprising. In Gulu the traditional birth attendants classified it under *'God's disease'* together with all other diseases whose cause and cure were unknown.

The research found many perceived predisposing factors across the five districts that included: promiscuity, multiple sexual partners, early sexual debut, sexually transmitted infections, poor personal hygiene, poor menstrual hygiene, intercourse during menstruation, partner physical/sexual mismatch e.g. size, use of modern family planning methods especially pills, IUDs, injections. Other perceived causes or risk factors included frequent deliveries, frequent abortions including those that are unsafe, using traditional herbs, eating certain foods e.g. oil distributed in IDP camps, poor diet, delivering when the cervix is not fully dilated and gases emitted by burning plastics in the environment.

Although people generally did not know that cervical cancer is caused by the Human Papiloma virus that in the majority of cases is sexually transmitted, across all five districts there was a general perception that the cause was sexually related. In all five districts untreated sexually transmitted diseases were mentioned as possible causes of cervical cancer and its transmission was specifically associated with promiscuity, early sexual debut among girls, intergenerational sex and sex relations outside prescribed cultural norms e.g. during menstruation.

In Mbarara the traditional healers mentioned *'obushanbani'* as the cause of cervical cancer, which literally means 'promiscuity' and *'endwara zobushambani'*, which literally translates as 'disease arising out of promiscuity' or 'disease that is sexually transmitted'. Cervical cancer was also associated with untreated STDs, which included *'enziku'* gonorrhea, and syphilis which was referred to in many different ways including *"ebihooya or ebinyoro or endwara yekiho."* Traditional healers suggested that men got those diseases from prostitutes and then passed them on to their wives who then developed cervical cancer.

In Soroti the traditional healers explained that when women get syphilis and or gonorrhea sometimes they choose to remain silent about them and eventually they become cancer. They observed that"

"As a result of women keeping quite these diseases waste away the uterus, prohibiting the woman from producing more children. They suffer silently and risk their bodies wasting away, they have to put up with the itching in their private parts and the STDs waste away their uterus and it becomes cancer"

In Gulu mention was also made of gonorrhea '*nyac abaci,'* which is believed to have been brought into the area by soldiers returning from war in Ethiopia *and* syphilis; or '*nyac gwok'* – which is allegedly got from dogs. Both were perceived to cause cervical cancer.

In Kampala as one of the gynecologists observed cervical cancer was believed to be directly transmitted from one infected person to another:

'Unlike other cancers, cervical cancer is believed to be a disease that is as a result of having sex with someone who has it and who then passes it on to their partners.'

In Soroti a similar belief was found to exist a private midwife explained that among the local people, cervical cancer was believed to be caused by inter generational sex, whereby old men who are rich are believed to infect young girls with the cancer. During the focus group discussion with senior women in Soroti other perceived causes emerged as illustgrated in the following quote:

"The main cause of this cancer among women is too much sex; risky sex is another cause of this cancer. This is because you cannot know whether a particular man is healthy or not. So you can come across a sick person and the sickness remains with you- inside your womb. Young girls should be told that once they reach the right age they should have sexual relations with men of their own size, they should not go with the size that is not for them (i.e. older men). Also they should not go anyhow, today this one, tomorrow that one (avoid multiple sexual partners) they should not change them like clothes. That is why you find that when one falls sick they will not know who has given them the sickness"

Traditional healers in Masaka also perceived early sexual debut among girls as a cause of cervical cancer they also attributed it to promiscuity and one contracting an STD and not getting proper treatment for it. Another perceived cause was attributed to deviant behavior. It was explained in Masaka that one of the cultural practices is the elongation of the clitoris; this is a process that begins when girls are still young and continues into their early teens. According to the traditional healers *'enyumba obutagalwa'* which literally meant that if the elongation is incomplete. It was reported that if the girls did not elongate their clitoris, they exposed themselves to germs and diseases. Related to this they also mentioned *'okwegatta nga okyakyalira ensiko* meaning that young girls who engaged in sexual relations before completing the process of elongating the clitoris also risked getting cervical cancer. It was believed that sexual intercourse during this time could lead to the bruising of the girls' private parts thus causing her to get a diseases which later turns into cancer. Traditional birth attendants in Masaka also mentioned engaging in sexual intercourse during menstruation as a possible cause of cervical cancer this was referred to as *"okwegatta ng'oli mu songa"*. Their explanation was that during menstruation the uterus is very soft and women's private parts are tender. They also mentioned *obwenzi.'* which literally means promiscuity. Women in Kampala also mentioned intergenerational sex as resulting in their uteruses/wombs being punctured leading to hemorrhage.

Also mentioned as possible causes of cancer of the cervix was poor personal and menstrual hygiene. Tradition healers in Masaka explained that poor personal hygiene caused many diseases including cancer of the cervix. They mentioned that some women and men did not bother to shave their overgrown pubic hair and to keep it clean. A male parent during the discussion also mentioned that:

"The majority of uncircumcised men do not know how to clean their private parts. They just pour water on the upper parts of their bodies and forget to clean the area covered by their foreskin on their private parts"

Poor menstrual hygiene was also mentioned as a possible cause of cervical cancer in four of the districts. Women who use dirty pieces of cloth instead of sanitary towels were perceived to be at a higher risk of contracting cervical cancer. The water used in the washing of underwear and menstrual cloths was also suspected to cause cancer, especially when the containers used to collect the water were not cleaned properly. Also mentioned was the soap used in washing genitals. Soap that is acidic was believed to be dangerous and to cause cancer.

In all five districts women who delivered many children were also perceived to be at a high risk of cervical cancer because frequent deliveries were perceived to weaken the womb.

Also mentioned as a possible cause was the giving birth to big babies who are heavy women in Soroti explained that:

"When a woman gives birth to many children then her uterus enlarges and lightens up and it can even burst… The uterus widens because the children are too heavy and this makes it easy for one to get an infection in the uterus. Once the uterus has become light it becomes susceptible to many diseases".

Also mentioned in all five districts as a cause of cervical cancer, was the use of modern family planning methods namely pills, IUDs and injections. In Kampala discussions with women and traditional healers revealed that they perceived family planning as sometimes hindering the normal flow of blood. The injections reportedly caused irregular periods but in some cases they also caused continuous heavy vaginal bleeding. IUDs were also associated with continuous heavy vaginal bleeding. The pills were believed to accumulate in the uterus and to cause wounds some of which later develop into cancer. Condoms were also said to cause cervical cancer because they have a pointed tip that rubbed against the womb and caused bruises, which later become cancer.

There were other perceived causes of cervical cancer that were mentioned but that did not cut across all districts. For example in Gulu cervical cancer was also believed to be caused by eating red meat; not eating a balanced diet and eating oil whose origins are unknown mainly associated with relief aid. Another factor was the sharing of facilities like toilets in internally displaced people's (IDP) camps. This was believed to lead to easy transmission of diseases, including cervical cancer. In Soroti other perceived causes mentioned were exposure to smoke arising from the burning of polythene papers, not eating correct foods, and eating food prepared with salt [Magadi] instead of soda ash. Witchcraft, curses and breaking of cultural norms were also perceived to cause cervical cancer. A private midwife in Soroti observed that:

"*They think it is witchcraft by the clan if the woman has broken some rules or norms or from her co-wife out of jealousy or mother in law. They say it is witchcraft or bewitching referred to as 'alogan' others say it is caused by a clan curse also known as 'ailamasit' or a broken cultural norm"*

In Kampala it was believed that if a foetus "gets lost" inside the womb for a very long period of time referred to as *"enkongolo"* cervical cancer could develop Difficult deliveries especially those unattended to by trained health personnel were also perceived to lead to cervical cancer. Women who deliver at home were perceived to be at a greater risk of cervical cancer because they reportedly developed complications including tears, prolapsed uterus and prolonged bleeding after delivery, which could later result in cancer of the cervix.

The majority of lay people did not know that the Human Papiloma virus causes cervical cancer and that in the majority of cases the virus is sexually transmitted. Across all five districts there was a general perception that the cause was sexually related. This was evident in the risk factors highlighted that included: promiscuity, multiple sexual partners, early sexual debut, sexually transmitted infections, poor personal hygiene, poor menstrual hygiene, and intercourse during menstruation, partner physical/sexual mismatch e.g. size, use of modern family planning methods especially pills, IUDs, injections. Other perceived risk factors included frequent deliveries, frequent abortions especially those that are unsafe, use of traditional herbs, eating certain foods e.g. oil distributed in IDP camps and poor diet.

4.5 KNOWLEDGE OF AND EXPERIENCES WITH VACCINATION

Knowledge of and experiences with vaccination were sought from boys and girls aged 10 to 12 years, male and female parents and from national and community leaders. The research explored what they perceived to be the benefits of vaccination/immunization, their experiences, their fears and misconceptions and their perceptions regarding the achievements of immunization programs.

4.5.1 Knowledge of vaccination and its perceived benefits

Virtually all of the children in and out of school reported that they had been vaccinated/immunized before and they knew the purpose. Most children had a good understanding of the benefits of vaccination/immunization, indicating that it was for disease prevention and protection, in particular against what they referred to as 'the 6 or 8 killer diseases'; that included measles, whooping cough, tuberculosis, tetanus, polio, meningitis, hepatitis B. The research found in areas that had experienced epidemics in the recent past like Gulu children included cholera. Children also reported that vaccination reduced the severity of diseases.

Children in-school appreciated the value of vaccination in preventing disease and noted that it protected them from serious illnesses:

> *"Immunization builds a firewall around us and prevents us from being attacked by diseases, it makes us immune from diseases and even if we suffer from those diseases we would not be affected for a long time…it is helpful to us in that it protects us from being attacked by diseases; ever since I was vaccinated against measles I have never suffered from it, it prevents us from being lame"* (FGD, Pupils, Mbarara)

The children noted the distinction between a normal injection as treatment for a particular illness and vaccination as prevention, as illustrated by this extract from an FGD with a group of girls in Kampala:

> *"Immunization takes place as a preventive measure against disease while a normal injection is given as a cure of a disease that one is suffering from. During vaccination, one may be injected on the shoulder or on the right arm but a normal injection is given on the backside. A vaccine may even be given in the mouth like in the case of the polio vaccine where drops are put in the mouth. Immunization means fighting against disease while injections cure us of common diseases"* (FGD, Girls, Kampala)

In Soroti, boys reported that they felt *"good, , secure and confident"* after vaccination, because they felt protected. In Gulu, several boys and girls explained why they liked being vaccinated, and what outcomes they had experienced following vaccinations:

> *"I like it because when you are immunized, nothing disturbs you in future"*
> *"When I was immunized, serious disease did not affect me"*

"I like it because there are certain diseases that could come in future that could kill you"

"I find immunization is good because the disease for which you are being immunized will not disturb you" (FGDs, Pupils, Gulu)

Like their counterparts in school, girls out of school also valued being vaccinated, saying they 'liked' it because of it reduces diseases.

Among the adults who were comprised of parents/guardians, community leaders, teachers, and other key informants at district and national levels, the research found that there was general knowledge of the need for and derived benefits of vaccination in terms of prevention of and protection against disease and in reduction of severity of diseases. There were even reports of observed declines in certain diseases,

"I understand that immunization retards the severity that a serious disease would have otherwise had on someone. If someone is immunized the effect of the disease is mild and the disease is easy to treat" (FGD, Parents, Mbarara)

"To be honest immunization has been very beneficial to us. In the past immunization used to be a threat but right now it has been put in check. In the same way, if a vaccine can be introduced to curb the damage caused by cervical cancer, that would be great" (FGD, Parents, Mbarara)

"A vaccine certainly prevents and protects the hosting body just as the English say, prevention is better than cure" (FGD, Parents, Mbarara)

While most parents in Kampala knew the importance and benefits of vaccinating their children, they were concerned that whenever a new vaccine was introduced, people were often not adequately informed about the side effects, they were only told about the benefits. In other words, no complete explanation about benefits and effects of the vaccine were given to the general population.

In Masaka, the majority of respondents knew about the protective effect/advantage of immunization against disease.

"Children are vaccinated to prevent disease because it is said that prevention is better than cure. Early prevention of disease is better than treatment of the same. In addition, if you catch a disease against which you've been immunized, you do not suffer in the same way as a person who was not vaccinated. This is what we see among children; the ones who have been immunized do not suffer from diseases in the same way as the ones who were not" (FGD, Parents, Masaka)

Some respondents believe that vaccination resulted in a cure of the disease, possibly meaning that it conferred life-long immunity or protection. This observation was made with regard to the measles vaccination in particular:

"We think immunization is a cure for all diseases and no disease can be cured without immunization.. If we take the example of measles, it is no longer the killer disease it once was. It is no longer as bad as it used to be and its outbreaks are not as widespread as they used to be" (FGD, Male parents, Masaka)

Parents also observed that they no longer saw cases of children suffering from diseases like polio this they attributed to immunization. They further observed that children whose parents rejected vaccination often fell sick or died whenever there were measles outbreaks. Parent also observed that children whose parents refused to get them vaccinated were more vulnerable to diseases, most notably to measles:

"Initially I refused to have my children immunized because we had been told that if your children were immunized they would die. I only had my baby immunized after I had realized that whenever it would fall sick it would become very weak and stay sick for a long time …When I gave birth I was advised by traditionalists to make the baby look face downwards into a pit latrine as a measure against catching measles. I was afraid to do it and so I decided to take my child to hospital for immunization. The child is now in P.5 and she has never suffered from measles. We used to hire a house in a place where there were many children and when they got measles it was an epidemic, but my child would survive it" (FGD, Female parents, Masaka)

Female parents in Soroti in particular, mentioned the benefits of vaccination against tetanus and polio in their communities. They understood that the unborn child was actually protected by the vaccines. In Gulu, similar remarks about the value of vaccination were made. Mothers in particular indicated that they were fully aware of the benefits of vaccination and that they had not seen common diseases vaccinated against affecting their children.

4.5.2 Associated fears and complications

While most of the boys and girls spoken to during the research appreciated the benefits of vaccination they also mentioned some of their fears and complications that they perceived arose from vaccinations. Those mentioned included: pain, swellings, or bleeding and in some cases death. Fears were also expressed about safety that included use of non-professional staff to vaccinate, vaccines being wrongly administered, reuse of needles, with possible dangers of contracting HIV infection; use of expired vaccines; overdosing; injecting on wrong sites that caused abscesses, wounds; and swellings like cysts. Apart from the common side effects mentioned, children were also concerned about other effects and complications that they had not necessarily experienced themselves but had heard about. These included: paralysis of the arm/limb; becoming mentally disturbed due to overdosing, or developing wounds that take long to heal. In a focus group discussion in Masaka girls brought out clearly their mistrust for those who conduct the vaccinations

:

"The health worker may be vaccinating the child when the needle breaks and gets stuck inside the body…

The nurse might forget and use a needle on more than one child…

An immunized child may get the spot where the needle touched to fester into a wound or becomes septic…

The drug inside the body may fail to spread and instead form a cyst…

The child may swell all over… He may develop a swelling on the buttocks, which may lead to having them cut off…

Some of these drugs are sometimes bad. The nurse may give it to the child without first reading the instructions, only to notice, too late, that the drug is expired…

*The nurse might give a child an overdose" (*FGD, Girls out of school, Masaka)

Concerns were also raised about injections being administered on wrong sites of the body as well as the manner of injecting. Some children also explained that they disliked or rejected immunization because of the re-use of injection materials, wrong administration of the injection, and possible transmission of diseases and other complications. Girls in Mbarara explained that children sometimes reject vaccination because:

They are frightened of the vaccine and fear the injection,
They come from the village and they are not used to getting injections,
Sometimes the immunization team uses vaccines that are damaged or tampered with,
One can be given an overdose,
My fear is that the person doing the immunization is likely to use a used injection which he has already used on another person and that would spread a certain disease to me like measles for example,
Some parents lack knowledge about the benefits of immunization,
Some people get injections shot in the wrong parts of the body then the vaccine goes to the wrong part of the body and the child becomes lame
An immunization shot can be put in a vein and this can cause death. Sometimes as they are administering the immunization shot, the needle can break (FGD, Girls, Mbarara)

In Kampala, reasons given by children for not wanting to be vaccinated were similar, mainly having to do with fears of the injection itself, fear of the medicine (vaccine) or its strength (potency) that it might spoil the arm, for example, cause paralysis; and fear that they might get some other diseases or infections following vaccination. In one school, girls reported that apart from pain, they associated vaccination with possible death, while others feared that expired vaccines used might cause death.

*"I was immunized and I disliked the way they injected me because they used force. I felt a lot of pain, but now I am happy" (*FGD, Pupils, Kampala)

In Soroti, suspected complications from vaccinations reported, were very similar to those expressed elsewhere. They included fears, such as the arms getting paralyzed and developing swellings after receiving the vaccines. In Gulu, some of the children also reported 'bad' experiences with vaccination – mainly the pain, swellings, or bleeding at times, that developed afterwards, or in a few cases feeling paralyzed in the limb. However, most of their fears were not about the vaccine itself, but more about the pain or process of administering the vaccine – the injection:

"I think even though I find it painful, it will help me in future"; "I don't like it when I am vaccinated, I keep bleeding and the area swells" (FGD, Girls in school, Gulu)

The research found that despite their knowledge of vaccination and its benefits many of the adults also had some fears and misconceptions with regard to vaccination. The concerns expressed were mainly about safety issues, such as safety of the vaccines, overdosing, and the training and competence of health workers or vaccinators used. In districts like Mbarara and Masaka where, private radio stations had run programmes de-campaigning vaccination programmes, parents reported that it took a lot of courage and counter-information to decide to take one's child for vaccination. For example, the Great Africa Radio run by a well-educated populist man, carried out a negative campaigns against vaccinations that left their mark on the population as noted by some FGD participants:

"The main reason for some parents rejecting immunization programs here is that, there is a certain radio which de-campaigned immunization programs and spread negative rumours about them. The radio is called Great Africa Radio, run by somebody known as Kaihurankuba. He planted a bad seed amongst our people and unfortunately some people took what he said as the truth" (FGD, Male parents, Mbarara)

In Kampala, women and teachers complained that they did not put much trust in the immunizing teams. They suspected that vaccines used might be expired, and that the staff only wanted to empty their stores of expired stocks. This level of distrust regarding the safety of vaccines clearly indicates the need to establish proper trust between service providers and users. One case was cited where, the Ministry of Education at one time mobilized for a vaccination program, and the school children were immunized, many suffered side effects, and some allegedly even lost their lives. These kinds of rumors cause true or untrue seem to cause a lot of suspicion and distrust of vaccinations.

4.5.3 Myths and misconceptions

The research found myths and misconceptions relating to vaccination; among them were fears that vaccines could cause infertility in girls or women. Another fear was that vaccination might well be a government plot introduced to kill off certain people, for whatever reasons, it was not really clear. The research found in districts such as Gulu and Soroti where there has been in the past political insecurity and insurgency reports that there have been negative political campaigns against vaccination at the community level, with some claiming that it is meant to control fertility while others say it is meant to exterminate certain ethnic groups. These myths have reportedly had led in some cases to poor coverage. Discussions with parents and community leaders in Kampala also revealed a range of issues that showed misconceived ideas about vaccination, including the thinking that when children were vaccinated, they were given some poisonous stuff intended to kill or harm them. Some of the parents could not understand why children often fell sick after vaccination, making them suspect that vaccines accelerated some diseases, yet, according to them, the vaccines were approved by the Ministry of Health, for use. These and other effects of vaccination such as children allegedly developing 'polio' (paralysis) after vaccination, were some of the reasons cited that discouraged some parents from taking their children for vaccination.

The research also found other myths relating to vaccination such as the belief that vaccines cause infertility in women, this was found across all the study districts; others believed that vaccination was being used to control or check the population growths of people in developing countries, or within countries as part of a political agenda. It was reported that some religions believe that people should not be protected against disease through vaccination but should instead pray for protection. Most of these myths and misconceptions were found to thrive on inadequate information.

Long-term de-campaigning of vaccination programs whether based on political, religious, or other reasons have had long-term negative effects on sections of the population. In all districts among all respondent groups, there were reports of such myths or misconceptions, some of which are exacerbated further by inadequate or inappropriate information from health workers. These are made worse when there are adverse events after immunization or other perceived side effects that have not been appropriately handled by the health workers due to an inadequate system to deal with the problem.

In light of these myths and perceived complications, the communication strategy and IEC materials need to address issues regarding the safety of the vaccine, accurate information needs to be given with regard to the vaccine and in as much as possible trained health workers should conduct the vaccinations. Information also needs to be given with regard to possible side effects following the vaccination.

4.5.4 Perceived achievements of immunization programs

The research found that declines in prevalence of some of the immunizable diseases observed by communities, has contributed to increased acceptance of immunization programs. This was mentioned by different categories of respondents. Diseases like measles and polio have reportedly showed the most significant declines. The results were reportedly obvious even to some community members who initially refused to have their children for vaccination.

> *"There is the good side of vaccinating, these days our children do not suffer from certain diseases like measles. There is not much TB. And thirdly, the disease that used to make children swell is no longer a lot these days. I think it is because they started vaccinating children early in hospitals that is the reason the disease is disappearing"* (FGD, Male parents, Gulu)

> *"Yesterday I was attending a meeting in which we all agreed that we have had a high percentage turnout for the immunized children. Very many children have been de-wormed and others received Vitamin C. These programmes were highly effective and successful and I am proud to say so"* (FGD, Male parents, Mbarara)

Success of vaccination programs in a number of areas was attributed to widespread sensitization and mobilization of the communities.

However lack of manpower to adequately cover the exercise, poor logistics managements and low vaccine supplies were mentioned as having led to some children

missing vaccinations, as observed by female parents in Soroti. It was also reported that sometimes people have to walk very long distances to get to vaccination sites and this is a challenge. This is an area that requires to be addressed as an aspect of an effective vaccine delivery system. Other aspects that need to be addressed have to do with who delivers the vaccine and handling of AEFI. In terms of acceptability adequate information needs to be made available to all stakeholders regarding the vaccine, its doses, storage, schedule etc.

The research found that most boys and girls aged 10 to 12 years had a good understanding of the benefits of vaccination/immunization, indicating that it was for disease prevention and protection, in particular against what they referred to as 'the 6 or 8' killer diseases. Among the adults who were comprised of parents/guardians, community leaders, teachers, and other key informants at district and national levels, there was general knowledge of the need for vaccination and the derived benefits of vaccination in terms of prevention of and protection against disease and in reduction of severity of diseases. Despite knowledge of the importance of vaccination and its benefits, some concerns were expressed regarding vaccination. The concerns mainly had to do with issues, such as safety of the vaccines, side effects, and the training and competence of health workers or vaccinators used. In districts such as Mbarara and Masaka it was reported that some private radio stations had run programmes de-campaigning vaccination programmes, parents reported that in the circumstances it took a lot of courage and counter-information to decide to take one's child for vaccination.

The research also found that declines in prevalence of some of the immunizable diseases observed by communities, has contributed to increased acceptance of immunization programs. This was mentioned by different categories of respondents. Diseases like measles and polio have reportedly showed the most significant declines. The results were reportedly obvious even to some community members who initially refused to have their children vaccinated.

4.6 Thoughts on vaccine introduction: Issues and Challenges.

Given that the cervical cancer vaccine is new and is meant for girls aged 10 to 12 years and is given in three doses, the formative research explored various stakeholders' thoughts on vaccine introduction and the likely challenges that they foresaw with its introduction. Across all 5 districts and at national level, the majority of stakeholders interviewed didn't know about the Cervical Cancer Vaccine (HPV). They heard about it for the first time during the formative research where the researchers provided brief information on the vaccine including the target age group, the doses, its schedule and what it was meant to protect against.

Based on the known benefits of vaccination, most of the respondents were positive about the Cervical Cancer Vaccine (HPV) especially after having understood the severity of the problem of cervical cancer. However, they expressed a need for more information regarding cervical cancer as a problem, the vaccine itself, its safety, side effects, experiences and results from where the vaccine had been tried out and reasons why 10 -12 year old girls were targeted. They particularly wanted the Ministry of Health and health professionals' endorsement of the vaccine. They also had concerns on the long-term effects of the vaccine

on the health and fertility of the girls. They wanted guarantees that it was not a new vaccine being tried out for the first time. They had fears that some politicians may use it for their own selfish reasons and some had suspicion that the government may be trying to use this as a way of controlling population growth especially in the north and northeast. In Kampala, where there have been vaccine trials in HIV, which have failed, concern was expressed with regard to the use of children as guinea pigs. The acceptance of the Cervical Cancer Vaccine (HPV) was partly dependent on the allaying of these fears.

4.6.1 Need for information and clarification on the **Cervical Cancer Vaccine (HPV)**

None of the children had heard about the vaccine and they expressed a need for more information about it as evidenced by the following quotes.

It should be explained what diseases it cures, and instructions for use.

They should gather us and tell us that all children are wanted at the Saza offices/grounds. There they should first counsel us and explain the type of disease they intend to immunize us against and also explain about that drug's effects.(FGD girls, Masaka)

While the community leaders were quite positive about the Cervical Cancer Vaccine (HPV) they at the same time expressed the need for more information regarding the vaccine and its safety.

If I could refer to the previous benefits, which we have reaped from the immunization against measles, I can safely predict that the immunization against cervical cancer will be valuable. You see when a child is immunized against measles, that child has the possibility of suffering a mild attack of measles or not suffering from measles at all. If people got to learn that we can reap the same benefits from the vaccine against cervical cancer then they would support the idea however they need to be assured that the vaccine is safe and that it will not have any serious side effects on the girls in future (FGD Community Leaders, Soroti)

There were a lot of concerns expressed with regard to likely side effects of the vaccine and the request for information on experiences where the vaccine has been tried. In Kampala in particular community leaders and teachers want to be reassured that this was not another vaccine trial. They reported that they had heard reports that HIV trials in Kampala have not yielded good results and this raised concerns on whether the Cervical Cancer Vaccine (HPV) vaccine was not indeed a trial of a new vaccine, raising concerns of not using their children as guinea pigs. Therefore people needed guarantees that the vaccine is safe and has been approved by all authorities in the health field including the WHO and Ministry of Health. It was explained that with these approvals, people would feel confident that the vaccine would not harm their children. Leaders were particularly concerned about this because they perceived their role as one mobilizing parents to take their children for vaccination. One of the religious leaders interviewed explained that:

As leaders we will need to know where the vaccine is coming from, whether the vaccine has side effects or not, whether it is not just being tried on people, where it has worked, and all the other details pertaining to it like has it been approved by WHO we also need to be sure that whoever is bringing it does not have other

intentions like wanting to control…It would also be useful to know the outcomes and experience of those individuals or girls that have been vaccinated in other countries. (Religious leader, Kampala)

While it was evident that people understood that vaccination is beneficial, they needed additional information regarding the Cervical Cancer Vaccine (HPV).

This immunization programme is excellent in its own right. However, most people including myself would benefit richly from sufficient sensitization and education. Particularly people would like to know the benefits that would come as a result of getting this immunization.

We would wish to know more about this vaccine and the dosage in general…. I think people should be educated about this immunization plan so that they don't regret in future. (FGD leaders, Mbarara)

There were concerns with regard to the 3 doses of the vaccine. Questions were raised as to whether 6 months was not too short a period for the girls to receive all 3 doses and whether this would not lead to an overdose. Children as well as adults wanted to know what the side effects were likely to be. There were indications that if the first dose had side effects, subsequent ones may not be complied with.

In addition logistic and potency concerns were also raised with regard to the vaccine that included: whether vaccines will not run out when the vaccination begins and whether recipients will be protected for life or booster doses will be required. The parents indicated that both parents and the girls will need to be helped to understand the need for completing the doses, the side effects and the dosing schedules. There were also concerns expressed on the targeted age group of girls and about the likely long-term effects of the vaccine on the health of these girls. These concerns depict the need for adequate information to all people involved. During the focus group discussions with parents they raised several questions:

I wish to seek more clarification ….Why is there a restriction that the age range must be between ten and twelve years?

There are parents who may have problems calculating the exact ages of their children.
If a child has gone up to thirteen years old, would that cause them any problem?
What if a child is twelve years and three months or so would that cause any trouble?
What if a child is nine years and five months would that be considered as under age? Lastly would this vaccine hamper the girls' sex urge in future? (FGD Parents, Gulu)

4.6.2 The need for endorsement of the vaccine by the Ministry of Health and health professionals

Community leaders, parents and teachers all indicated that they would be looking to the Ministry of Health and health professionals to endorse the vaccine. These were reportedly respected authorities on health and would be looked to for advice. One of the community leaders indicated that:

If the Ministry of Health has approved the vaccine and advocates for it, I shall surely support it fully. The reason why I maintain this opinion is that I have seen women suffering from cervical cancer and felt pity for them.

People emphasized government's role to be the leader in ensuring this vaccine introduction is implemented. The following quotes highlight this.

In my view the government is the one to decide for her people because once it passes such a programme as a decree everyone will be forced to take part in it. The reason why I think government should be the sole deciding body is that it is well aware of the effects of this disease while we don't. If government leaves the people to decide on their own it could be running into a risk of many people refusing to take part.(FGD Teachers, Masaka)

Government should play a leading role in decision-making. If people are left to choose many of them will automatically opt not to take part. For example, when Universal Primary Education was introduced parents were asked to pay a mere 2,000 shillings to the fund of Parents Teacher Association (PTA), which most of them refused to pay. Since this programme has got health implications, the government needs to take the upper hand in decision making.(FGD Parents, Masaka)

There was an expressed need for government to take a lead role. It was explained by several of the parents that even people who are educated and are expected to guide the uneducated sometimes do not do so. They indicated that they have been known to actually interfere with vaccination programs by giving wrong advice to people. Community leaders felt strongly that government should to take the lead although they also acknowledged the important role that parents would have to play:

The Ministry of Health should be strict about certain issues especially if something is really good for people and will actually prevent people from getting diseases. Our people are undecided and will complain even when they really want something. Our people will always be in doubt. I don't believe it is only people who have been to school who are wise; some people have gone to school but they say things that are not befitting of their level of education. That is why I say that the ministry itself should give this issue time.

Government must decide and decree that girls should be immunized because they are the ones who take the initiative to provide medicine in hospitals and health centres… Not withstanding, parents should have the final word, because if government forced parents to get their children immunized and something went wrong then government will be held accountable. (FGD, Community Leaders, Gulu)

Questions were raised by community leaders as to whether government had already put in place mechanisms and policies to guide implementation and if it had ensured that the vaccine is safe for use in Uganda. Safety seems to be paramount to the success of this vaccine introduction.

Has the government introduced any policy on this kind of immunization, or has it accepted? If people use it and get side effects, then that will be the end of it. Therefore before they introduce it, they should make sure that the vaccine is well tested with no side effects. We should also know that if some children get side effects, then it would hinder the progress of the new vaccine. So however much a policy

emphasizing immunization is put in place, parents will not take their children for vaccination if they hear of such issues.(FGD Political Leaders, Kampala)

4.6.3 The need for information on magnitude of cervical cancer as a problem

Another issue that arose during the formative research was the question to what extent is cervical cancer a big problem that warrants the introduction of this vaccine in Uganda. It was evident that people first need to understand that cervical cancer is a big problem and that it therefore warrants this intervention, as this quote from one of the cultural leaders illustrates.

Given what you have told me about cervical cancer I think it is a good thing that a vaccine has been developed to prevent it, however whoever is planning to introduce it to the public has to be very careful. Initally we had problems with immunisation in the kingdom, with people refusing to have their children immunised it took a lot of sensitization to convine people of the value of the exercise. There is need for a lot of sensitization before the new vaccine is announced or even introduced, so that people are already aware of it otherwise there are likely to be problems. People will ask me "have you joined these others to kill our children" . To begin with people do not know enough about cervical cancer as a problem, so they need to first of all understand it as a problem. We can always organise a program on radio where people can be given information and questions and seek clarifications. (Cultural leader_ Minister of Health Buganda Kingdom, Kampala)

Among the issues that the IEC materials will need to address will be the burden of cervical cancer. Information needs to be presented to the general public on the magnitude of the problem and why it is necessary to introduce this vaccine.

4.6.4 Fear of politicians hijacking the process

Parents expressed concern that there are cases in the past when immunization programs have been politicized. Fears were expressed that some politicians may use the vaccine to serve their own political goals. Head teachers and parents reported that there were people who sometimes de-campaign government program even when they know the benefits of such programs by claiming that immunizations are politically planned by the government to kill their children as observed below:

Sometimes parents are against these immunization programs. Some of them take them/consider them to be political, saying that the politicians/government wants to kill the children. For example in 1989, when a measles vaccine was administered to the children, some children turned 'abnormal' for example they couldn't talk, felt sickly. So basically, some parents still have a negative attitude towards immunization. (FGD, Parents, Soroti)

In Gulu and Soroti, leaders were cautious about the possible suspicions that may arise with introduction of the new vaccine given their recent history with insurgence that has been politically motivated. The religious and community leaders had concerns about groups that don't believe in modern medicine, which could discourage people from getting the vaccine. In Mbarara, there is even a history of de-campaigning immunization programs by the media with allegations of controlling population. While people were not objecting to the vaccine as

such, but they needed information [more] on the vaccine to allay issues of safety, side effects, and why children 10 -12 yrs were targeted.

Based on the known benefits of vaccination, most respondents were positive about the Cervical Cancer Vaccine (HPV). They however expressed a need for more information regarding cervical cancer as a problem, the vaccine itself, its safety, side effects, experiences and results from where the vaccine had been tried out and reasons why 10 -12 year old girls were targeted. They particularly wanted the Ministry of Health and health professionals' endorsement of the vaccine. They also had concerns on the long-term effects of the vaccine on the health and fertility of girls and indicated that they would like guarantees that it was not a new vaccine being tried out for the first time. They had fears that some politicians may use it for their own selfish reasons and some had suspicion that the government may be trying to use this as a way of controlling population growth especially in the north and northeast. In Kampala, where there have been vaccine trials in HIV that have failed, concern was expressed with regard to the use of children as guinea pigs. The acceptance of the Cervical Cancer (HPV) Vaccine therefore is likely to be dependent on the provision of accurate information and on the allaying of such fears through an effective communication and advocacy strategy.

4.7 Decision Making with Regard to the vaccination of Children aged 10 to 12 years

The formative research explored who the primary and secondary decision makers would be with regard to vaccination of girls aged 10 to 12 years. This question was posed to children in and out of school, parents/guardians, community leaders, head teachers and teachers, senior women, as well as political, cultural and religious leaders. The majority of respondents indicated that the primary decision makers were likely to be the girls' parents/guardians but most especially their mothers. However it was also pointed out that if the vaccination took place in school, the primary decision markers could be others other than their parents. The research found that in urban schools if a vaccination program was to take place, consent was normally sought from their parents their decisions were normally respected. However in rural schools once the health department agreed with the schools no consent was sought from parents they were just informed of the planned vaccination program sometimes through their children or through the radio or the local council system. Children were then vaccinated at school. It was reported that those parents who did not want their children vaccinated kept them at home on that day but otherwise teachers and head teachers seemed to be the primary decision markers in this case.

4.7.1 Children as decision makers

An issue explored in the formative research was whether children aged 10 to 12 years were primary decision markers on issues relating to their health. Parents, teachers and other stakeholders were asked whether children could make their own decisions regarding being vaccinated. Education department officials reported that children usually have to assent. This was also reiterated by an official from the National Council for Children who further explained that the statue for children states that children are required to assent and that this took precedence over their parents' consent.

Some of them will have known about the usefulness of the vaccination and will want to be vaccinated even if their parents do not want them to. They learn about the importance of vaccination at school, so when it comes, they can decide to cooperate" (KI - District Inspector of Schools, Mbarara)

It depends on age. Those who are young 6-8 years out of fear cannot, but those who are older, can. They just go and line up for the services" (KI - Municipality Education Officer, Gulu)

Others emphasized the role of parents consent:

I think at that age children are still young and are obedient to their parents. It is difficult for a child of that age to say no to their parents. They are still under the control of their parents". (FGD, Male parents, Masaka)

"For a child to decide for her/him self, it depends on the age. Those who are young like 6-8 years out of fear cannot, but those who are older can. They just go and line up for the program…. "Yes, because some of them will have known about the usefulness of vaccination. They learn about it at school, so when it comes, they can decide on their own". (KI, Municipality Education officer, Gulu)

However, there was a general recognition that children aged 10 to 12 years would have a role to play in deciding whether to be vaccinated despite being minors, under parental control. Parents and teachers observed that children these days are assertive and know what they want as illustrated in the example below.

"Parent may refuse children from going to a film but if the children are interested they will surely escape through windows and go out. Similarly if children choose to be vaccinated at school, while their parents are busy attending to their farms, they will get home and refuse to entertain questions from their parents about immunization". (FGD, Female Parents, Mbarara)

It was also noted that girls who are 10 – 12 years could be talked to and helped to understand the benefit of being vaccinated.

"If I talk to my daughter when she is ten years old and she refuses to take part I shall continue talking to her. I shall also show her people who have also taken this immunization. I shall not stop talking, encouraging her, enlightening her and showing her examples. Hopefully by the time she turns twelve she will have made up her mind to be immunized".

"I would do my level best or I would do everything it takes me to ensure that I get my daughter to consent willingly. If she became obstinate, I would ask other people to talk to her with a view to persuading her. I would most likely ask people who are not family members. You see some children tend to have more faith in what people outside their family believe. I would keep up the dialogue open between my daughter and I to enable her understand the purpose and later consent". (FGD Female Parents, Kampala)

It was felt that information needed to be given to the children about the disease, including it causes, signs and symptoms, and how it can be prevented, as this would motivate them to willingly assent to being vaccinated as in the quotations below.

"I am positive that if we inform our daughters and furnish them with crucial facts about the disease (cervical cancer) they will definitely allow to be vaccinated. For example, if we let them know that cervical cancer is a killer disease, and that it has no cure I surely think that, they will easily accept to be vaccinated". (FGD Male parents Gulu)

"Certainly if a child has been educated about this disease; if a child has been taught about the effects of this disease; if a child has seen a film with the theme of this disease and if a parent has full knowledge of this disease therefore I do not foresee any situation whereby a child will refuse to be immunized". (FGD Male parents Kampala)

"I would have to sit my child down and explain the advantages of immunization and the problems that may follow if she is nit immunized". (FGD Male parents Masaka)

According to political and religious leaders while parents are normally the primary decision makers on children's vaccination they do so especially for much younger children. Ten to 12 year olds were in between. While they could be influenced by other people, like the leaders, health workers and teachers they could also decide and assent on their own. Leaders also noted that health workers could influence some of the decisions by convincing them about the safety of the vaccine in question.

4.7.2 The Role of parents

From the perspective of children in school, it was reported that the decision as to whether girls aged 10-12 years should be vaccinated would mainly be influenced by their mothers at home or by both parents, and often by teachers (school authorities) at school. They explained that parents in most cases complied with the requests sent from school through them in addition to information given within the communities. A Male parent in Mbarara had this to say:

"I am of the view that children need to look to their parents for guidance. For example if a parent advised a child not to take a path because it was thorny but rather to take a particular path because it was straight, a child would obey. I am positive that parents have a certain amount of influence on their children to the extent of getting them to do certain things". (FGD, Male parents, Mbarara)

Discussions with girls from an urban primary school in Masaka revealed that the decision to take the cervical cancer vaccine would depend on their parents, who they said would take the responsibility to ensure that the girls go for vaccination. They reasoned that their parents would agree because of the perceived advantages, which included their daughters being free from the disease in their adulthood.

When parents were asked who would decide whether their girls should be vaccinated still there were mixed reaction as expressed below.

"In my opinion the issue of decision-making lies with three people: father, mother and the child to be immunized. You see these days children have found a voice and we need to consult with them in issues that concern them." (FGD Parents, Mbarara)

Mutual communication is crucial in determining whether children should be immunized because if the parent says no then the children will follow their opinion.

> *"Both of us have to agree about It, but even if both of us have to decide, if my wife refused I would push to have my child immunized. But both my wife and I concur that our children should be immunized because we are fully aware of its advantages. I also agreed with my wife that we should take my children for immunization more especially after hearing all the radio announcements."* (FGD Parents, Mbarara)

In urban areas like in Kampala, mothers were looked at as the main decision makers in most cases, but sometimes both parents although this varied from responses given by those in areas. Fathers usually cared very much about issues concerning immunizing their children, although there were cases where fathers refused their wives to take their children for immunization threatening them that in case they did so, they should not return to their homes.

> *"if you know that the child is mine, do not take them for immunization, if you do then do not return to my home" even if the mothers wanted. Sometimes they would be threatened with such threats and would fear to go ahead, while others do so secretly".* (Political leader, City Woman Councilor, Kampala)

Same sentiments were expressed from political leaders in Gulu, Soroti, and Masaka.

> *"If you know that the child is mine, then do not take them for immunisation, if you do, then do not return to my home".* (Political leader - City Woman Councilor).

It was revealed that such vaccination programs are initiated through the ministry of health and it is the ministry that is responsible for deciding whether children should be vaccinated. It comes as a policy and it is the government that decides all the vaccinations on behalf of its citizens. In Kampala for example, it was also reported that mothers especially in the urban areas are responsible for their children's health, and that it is their responsibility to decide about children being vaccinated if convinced.

> *"It is the responsibility of the mothers to take care of their children, including their health and that men play a less role in deciding issues concerning children's health more especially in the urban centers due to social class and status, although their role is more visible among those in the rural areas.* (Political leader, Minister for Gender, Kampala)

> *"We as political leaders, our role is to promote the government policy by going down to the communities and sensitizing them on the benefits of the vaccination program in order for it to be accepted". (*Political leader, Secretary for Health, Education and sports, Kampala).

> *"It is the government that makes laws and policies, community leaders and us the religious leaders then have the task of telling people whether to go for the service or not, although it is purely the responsibility of the parents to either accept or refuse their children to be vaccinated".*

"Mothers of children are responsible for deciding whether children should be immunized or not, although those that are considered grownups make their own decisions, but the young one cannot decide whether to be immunized or not". (Religious leader, Kampala)

A number of respondents were willing to have their daughters vaccinated. The views of the different respondents are presented below.

"Personally, I will hand my child over to be immunized, since we have come to this modern method of preventing cervical cancer that is also how it was with measles. It was first resisted but late it was observed that almost 90% of those who were immunized did not catch the disease or at worst only had mild attacks so if this programme came and we were properly educated about it, I would allow my child to be vaccinated". (FGD, Political Leaders, Kampala)

In Gulu it was reported that the decisions to have girls vaccinated would most likely be taken by both parents; most often the mothers or after consulting with their spouses/ husbands. It was also reported that the school management sometimes make the decision on behalf of the parents or guardians. Local community leaders reported that decisions on vaccinating children were mostly taken by parents, while at school teachers often took the decision after communicating with the parents through the children.

Discussions with different categories of parents across all five districts revealed that the majority willing to have their daughters vaccinated if a number of issues could be clarified for them these included being assured that the vaccine is safe, effective and with no side effects. They also suggested that there was a need for a lot of sensitization in the communities, for example one respondent indicated that in as far as they were concerned they could consent for their child to be vaccinated because they knew the benefits of vaccination, but there were those who were not informed about the benefits.

4.7.3 Role of Schools

The research explored whether when vaccinations took place in schools, the school administrators sought consent before vaccinating the children. Discussions' with teachers and other school authorities revealed that schools do not usually seek prior consent before children in their schools are vaccinated since such activities are normally considered national programs. It is assumed that parents have heard the announcements made by the Ministry of Health regarding the vaccination activities over the radio.

"I do not think they seek prior consent, the programmes are normally aired out on radio and the parents know that their children will be immunized" (Municipality Education Officer, Gulu)

Discussions with the School Management Committee in one school in Kampala revealed that normally the Ministry of Health informed the schools and the schools then write letters to parents through their children informing them about the vaccination exercise as described below.

"Normal the Ministry of Health has to inform the school, the school then has to write letters for these children to take to their parents informing them about immunization. Schools write letters to parents; and even keep announcing on parades, so that children keep on reminding their parents about the date of immunization". (FGD Senior woman science teachers, *Kampala)*

However, discussions with some parents in Kampala revealed a case of a private school where children are given letters to take to their parents informing them of the immunization exercises to take place. After establishing that the age is within the age-bracket specified for immunization, the school would communicate to the parent in writing. Parents reported that those who did not want their children to be immunized would keep them at home on the day of immunization and send them back again after the exercise. This conforms to the view of cultural/community leaders who argued that the decision to immunize a child entirely depends on the parent as observed below:

"I think it is parents who normally decide that their children should not be immunized. You cannot immunize a child when the parent has not agreed, therefore It is government, the Ministry of Health together with parents that decide". (KI Political leader, Gulu)

Head teachers and school management committees in Gulu reported that they sought the consent of parents by sending messages through the school children, in compliance with directives of the district health office. Senior women and science teachers also concurred that schools generally seek prior consent of the parents, but some of the bigger children often decide for themselves. Senior women teachers are normally involved in organizing the children – especially girls – once the vaccination program has been confirmed. They see such decisions as being taken by the head teacher and the medical people.

The education officials in all the five districts reported that pupils in schools were generally not vaccinated without their parents' consent; however, it was also evident that parental consent was not always sought. An assumption was made that when health unit staff through schools administers vaccination programs, they are government programs and are assumed to be safe. However for parents who did not want their children vaccinated, they kept them at home the vaccination period to avoid being vaccinated.

Experience with TT vaccination revealed that some girls refused to be vaccinated and run away and the schools could not force them. It was explained however that after sensitization of the pupils, parents and the community as a whole could talk to their children convincing them, so long as the parents understood the benefits of being vaccinated. This is mainly in government schools; some private schools do not want to provide anything to their children without consulting their parents first. This is mainly due to fears of what may befall them especially on issues concerning vaccination, cannot easily be done more especially in urban centers.

It was explained that normally the Ministry of Health provides messages on radios, the local media and also posters in schools, clearly specifying the date on which the vaccination programmes would be held and in some cases, talks were given on some of the benefits of the vaccination exercise. Interviews with an education officer in Kampala revealed that

private schools like Kampala Parents, would not easily allow pupils to be vaccinated without the consent of their parents unlike in some of the rural schools.

There were similar responses regarding who makes decisions concerning the vaccination of children especially to those in schools. Interviews with education officials and discussions with parents revealed that schools did not seek prior consent from parents before the children were immunized. One Deputy headteacher explained that mobilization and sensitization is normally done by LC chairpersons and by using loud speakers in the trading centers and communities to ensure that parents are informed about the exercise and thereafter children are immunized at schools. Teachers also reported that parents are informed about the immunization exercise during the general meetings.

Group discussions with fathers in Masaka revealed that as parents who trust the schools, they did not find it necessary for the school to seek their permission to immunize children; stating that after all they gave schools their children and that teachers are also parents. There would not be any problem vaccinating children at schools. This varied from some responses provided in Kampala, where it was reported that children should not be vaccinated at school unless consent from parents is sought.

According to some education official in Masaka, it was reported that they do not seek the parents consent, and that parents were sensitized by the LC Chairperson, and that during immunization times, they did not have to seek parents' consent because the parents will have already been sensitized and will know and accept that their children be immunized. However, it was important to note that parents are very influential and can refuse their children from being immunized. They also reported that as long as the children are at school, they are immunized irrespective of whether the parents accepted or not. The children simply follow the order or arrangement done by the school. For example, if it is primary one, then all are immunized, unless for those few who fear injection.

It was evident from interviews in all the districts that schools did not at all times seek prior consent from parents before the children were immunized in school. According to one of the education officers, no prior consent is sought since the programmes are normally aired out on radio, and the parents know that children need the immunization. Also mentioned as being important in this decision making process apart from parents were teachers (especially senior women teachers), local leaders (LCs), PTA members, and district political leaders.

It was pointed out that there is a policy in school that requires a child to have an immunization card to be registered. It was mentioned further that there was a directive from the district administration for schools to ask for immunization cards. However, it was noted that there were parents who refused to have their children immunized but these eventually accept after being sensitized.

Regarding what would happen if girls did not want to be vaccinated and their parents wanted them too, in all five districts, various stakeholders reported that this would be unlikely, since children this age can be persuaded to follow decisions made by their parents.

"*It would be very unlikely, it would come if the children themselves do not know or understand the immunization for example if they are explained to, , what cervical cancer is, and the causes and effects, and that it is only avoided through immunization, then they would understand all causes and effect, and will have no reason to refuse as 12 year old are old enough girls, and thus cannot refuse".* (FGD Parents – Kampala)

In the event of girls refusing to get vaccinated, the leaders believed this would only arise from lack of awareness on the benefits and therefore proposed that the recipients of the vaccine should be educated to ease acceptance. Some respondents even suggested corporal punishment for errant children. On the part of parents refusing the vaccine, the majority of leaders indicated that children would still go for it even without their parents consent if they believed it was useful. If parents refused, they would be obliged to explain why, to the children. It was observed many children now know their rights and the right to be immunized is one of them. Such parents could be reported by their children to the Local leaders (LCs) who may in turn sue or reprimand the parents.

"The child may even sneak and go to get the vaccination without your knowing. The child may report a father to the LC and the father can be sued. $The Child may even involve other people like neighbors who will talk to the parent and encourage him to take his child for vaccination." (Local Leader, Kampala)

Sometimes harmful propaganda may be spread which may affect people's decisions to have their children vaccinated. This may stem from the fears that the vaccine may have birth control effects since only girls are targeted.

"People may say that this vaccine causes other illnesses or may be it stops one from being able to bear children. Some may think that the government wants to reduce the growing population; they may wonder why it is only girls and not boys too. They may think the vaccine causes other complications in the body."(KI- Political leaders Soroti)

To address these attitudes it was proposed that there is need to mobilize and sensitize people to make them understand the vaccine. This effort should not only be done by experienced professionals but also involve mothers and opinion leaders. So while negative attitudes can severely affect acceptance of the vaccine, the solution was perceived to be that of providing factual information through the popular media like radios, and also the local leadership. Community leaders explained that form them to be able to provide informed advice to advise effectively, they have to be well informed on the vaccine, especially its effects, whether good or bad.

"To do this, they would need information on the cause of cervical cancer, plus the advantages and disadvantages of the vaccine. In this same vein, as a leader, I need or would normally consult the community and technical people before making a decision."(KI- Political leaders Soroti)

It was felt that mothers understand their children better and would be in a better position to educate them and therefore influence their decision to accept the vaccine, calling on the father only when they fail to convince the children. Fathers, were reported to have more powers in the home, and would be expected to emphasize to children who may disobey their mothers.

Whereas the male parents indicated that the decision to have the girls vaccinated would be decided by one or both parents, the female parents said that this is usually decided by the responsible government departments and officials. It appears the female parents would accept anything decided by government without question. Refusal from parents would arise out of ignorance of benefits, lack of care of their children's welfare, inability to appreciate value of vaccination since they never got vaccinated themselves as children. The female parents listed negligence, laziness, and fear of side effects like infertility or crippling to affect their decision-making.

4.7.4 Perceived influencers of decisions relating to vaccine introduction and acceptance.

Those perceived to be influential when it comes to vaccine introduction and acceptance included Church Leaders, LCs, Teachers, and Parliamentarians (political). Discussion with parents in Kampala revealed that those in the communities like the political leaders, church leaders and the community leaders were reported to be only responsible for promoting the utilization of the vaccine, and ensuring that they sensitize the public about it, if given appropriate information about the vaccine.

In terms of who could be consulted before making decisions to have daughters vaccinated, various stakeholders in nearly all the districts mentioned health workers, who were believed to be informed on health related issues.

> "*Health personnel because they tell us a lot of issues concerning the vaccine, including its benefits and side effects."* (FGD – Parents Kampala)

> *"If Muslim Sheikhs, Catholic bishops told the people to take their children for immunisation, they would do it because they consider the involvement of these religious leaders a proof that the vaccine is genuine. In the same way if a religious leader tells the protestant congregation to take children for immunisation; the people believe in such people more than in others. I would also think that the Kabaka of Buganda contributes a lot towards immunisation especially here in Buganda. When he took his own child for immunisation, many followed his example. It is also necessary to go down to the grassroots and involve the LC chairmen because people heed their word a lot. Teachers in schools also contribute a lot towards our children. They should also be involved in that activity. If we tell them and they participate things would move smoothly."* (FGD – Parents Kampala)

Respondents mainly the political leaders in all the five districts indicated that with the multiparty political system of governance where every program is politicized, political and community leaders should be sensitized so that they know the benefits of such programs and are able to give informed advice to the communities that they serve. Otherwise there was a fear that if adequate sensitization is not done, then the program will meet a lot of resistance and its intended purpose may not be met.

From the perspectives of the political leaders in Kampala, they believed that if properly briefed, it would be a very good intervention that would save a number of women. They observed however that the problem would be if the introduction of the new vaccine is filled

with misconceptions surrounded by rumors as this is sometimes the case. Other political leaders revealed that if they are convinced that the vaccine is good with no side effects, and told clearly what the benefits are, then they would freely encourage their daughter and others in the community to be vaccinated. But if they got to know that there is a hidden agenda with the introduction of the vaccine, like being a birth control method, then it would not be very easy to accept.

A religious leader in Kampala indicated that he could not easily consent to his daughters' vaccination until he received assurance about how efficient and effective the vaccine. This reassurance was requested by the majority of the community leaders

> *"Personally if I am convinced that the vaccine is safe, effective and with no side effects, then I do not have any problem with accepting my daughter to be vaccinated". Political leader - KI_Kampala (Secretary for Health Education)*

> *"With this new vaccine as a political leader, I would encourage mothers to take their children for immunization, only if I am very sure that the vaccine works, that the vaccine has no side effects, but personally, I would not freely allow my children or daughters or grand daughters to be vaccinated, unless certain questions are very well answered like since the children are vaccinated when they are still young, how will we know that the vaccines have been effective in our children's bodies."* Political leader - KI_Kampala (Minister for Gender)

Religious leaders in Gulu considered the most important aspect as, having clear information from very reliable sources like the DHO, and other sources including the medical bureaus, professional bodies or even the WHO. They also said that they would first consider the reaction or opinions of the parents before guiding them to make informed decision, basing it as a health matter. Political, traditional/community leaders were mentioned or identified to be among the people to be consulted before making a decision about vaccinating. The main reason was that they exert a lot of influence on the population, and can more easily convince the community about vaccine safety, but only after they themselves – the leaders, have been sensitized and assured of its safety by the health workers or technical people.

Community leaders in Gulu Municipality suggested that among the important things to consider before deciding on introducing the vaccine should be government policy and sensitization regarding the benefits and/or advantages/disadvantages of accepting the vaccination. Such information (especially on the benefits) would go a long way in informing parents before taking the decision. Head teachers and the senior teachers emphasized the fact that parents needed adequate information before the vaccine is introduced, and they suggested training for themselves in order to be fully involved, requiring adequate information ahead of introduction of the vaccine.

Health workers also emphasized the need for accurate information being given to parents as well as different leaders at all levels, and envisaged positive response from the parents since, and according to them, though there might be some misgivings and misconceptions, parents were more relaxed regarding vaccination of older children than vaccination of younger ones. In terms of acceptability of the vaccine; male parents

highlighted the value of prior education on the benefits of Cervical Cancer Vaccine in increasing its acceptance. The female parents added that children who are able to read should be given simple leaflets to read. Involvement of local leaders is good lead if they embrace the Cervical Cancer Vaccine. If they participate in sensitization, acceptance would be high.

> *"As I have just mentioned, prior education on the benefits of the vaccine will definitely lead to high turn up or acceptability of the vaccine. LCs at the village are our leaders. If they are involved say trained and used to sensitize the masses, people know them and will therefore ensure girls receive vaccination."* (FGD, Parents and Guardians, Soroti)

The formative research explored whom the primary and secondary decision makers would be with regard to vaccination of girls aged 10 to 12 years. The majority of respondents indicated that the primary decision makers were likely to be parents/guardians but most especially the mothers. However it was also pointed out that if the vaccination took place in school, the primary decision markers could be the school administrators other than parents. The research found that while in urban schools consent was normally sought from parents and their decisions respected, in rural schools once the health department agreed with the schools no consent was sought from parents. Parents were just informed of the planned vaccination program sometimes through their children or through the radio or the local council system. Children were then vaccinated at school. It was reported however that those parents who did not want their children vaccinated kept them at home on that day. There was also general recognition that children aged 10 to 12 years would have a role to play in deciding whether to be vaccinated or not. Parents acknowledged that children in this age group could accept or refuse to be vaccinated. Furthermore parents also acknowledged that while they have the final responsibility to consent to their children's vaccination the more important role would be to encourage and support their daughters to complete all three doses of the Cervical Cancer (HPV) Vaccine. Others perceived to be influential when it comes to vaccine introduction and acceptance included Church Leaders, Local Councils, Teachers, and Parliamentarians.

5.0 FINDINGS: VACCINE DELIVERY COMPONENT

The vaccine delivery component collected and analyzed data on vaccine delivery system options in Uganda, including relevant structures, processes, and capacities in the Ministry of Health. It identified needs specific to the HPV vaccine. Furthermore the research examined the suitability of existing institutional structures (e.g., schools, primary health services) for delivering HPV vaccine to pre-adolescents in communities. The perceptions of key stakeholders regarding the capacity for these institutional structures to deliver the HPV vaccine and the impact that the introduction of the vaccine is likely to have on selected services and staff were also explored. This chapter presents and discusses the findings from this research component.

5.1 Assessment of existing institutional structures for delivery of the HPV Vaccine

The research assessed the suitability of existing institutional structures such as health services and schools for delivering the HPV vaccine to children aged 10 to 12 years in communities. It also explored the perceptions of key stakeholders regarding the capacities of these institutional structures to deliver the HPV vaccine

5.1.1 School based health services and initiatives

The formative research explored the availability of health services designed specifically for pre-adolescent children (10-12 years). The study found that no such health services existed. It was reported however that government in collaboration with development partners had plans to revitalize the School Health Program with the aim of providing health services for children in school.

The research found of several initiatives in schools that provide health education and life skills training for children in this age group. Among those mentioned were The Presidential Initiative on AIDS Strategy for Communicating to Young People (PIASCY), African Network for Child Protection and Prevention of Negligence and Abuse (APPCAN, Boys Scouts and Girl Guides. PIASCY was reported across all five district as an important channel through which primary school children were provided with information on all aspects of health including HIV and AIDS. This initiative was reported to be popular in most primary schools in the country.

Other agencies such as UNICEF, Hope after Rape, African Network for Child Protection and Prevention of Negligence and Abuse (APPCAN), were reported to be supporting the formation of clubs in schools where school children are sensitized on a wide range of issues including taking good care of their health. Furthermore senior women teachers run special sessions with girls where they discussed issues of personal hygiene, sanitation and sexual maturation.

5.2 Vaccine Delivery Strategies

Various stakeholders were asked what they perceived to be the most appropriate strategy for delivery of the HPV vaccine to pre-adolescent girls both in and out of school. Several strategies were suggested each with its pros and cons. The different strategies suggested for the delivery of the HPV vaccine to pre-adolescent girls included: its introduction as a stand alone project, its integration into the Child Days Plus Strategy which reaches out to children both in and out of school and combining the HPV vaccine with that of the TT.

5.2.1 Stand Alone Strategy

Those that perceived the stand alone strategy as the most appropriate argued that: the target group for the HPV vaccine (10 to 12 year old girls) was outside the age group of children normally covered by routine immunization programs; secondly there were currently no health services specifically designed for this age group where this vaccine could be easily integrated, furthermore it was argued that because the HPV vaccine is new and given the age group that it targets there was need to devote more time and resources to community mobilization and sensitization and that this attention would only be possible if the vaccine was delivered as a stand alone other than integrated into the routine vaccination programs.

The district based technical and administrative staff and political leaders advocated for this strategy arguing that it would be easier and quicker to implement as a stand-alone especially if it came with its own budget rather than relying on the PHC funds that covered many other health activities in the districts. It was further argued that as a stand alone the necessary staff needed to conduct the vaccinations would be deployed and they would be able to concentrate on this exercise unlike in the routine immunization programs where their attention was sometimes divided. It was further argued that once the public was aware about the HPV vaccine and had accepted it could then be integrated into the routine vaccination programs

Using the stand-alone approach is better than using the routine approach. In a stand-alone you bring all the staff once, deploy them once, carry out the exercise in schools for 3-4 days and then plan for the next round. This is cheaper. Under routine immunization you will have staff shortage. With the stand-alone you will mobilize and get the target group. (District Health Officer, Masaka)

The stand-alone strategy was also perceived as providing the opportunity to 'observe how vaccination with HPV vaccine is implemented and accepted before being integrated in other vaccination programs. It was argued that with this strategy even if the HPV was rejected this would not affect other routine vaccination programs.

The major disadvantage highlighted with regard to the stand-alone strategy was that it is very expensive in terms of resources both human and financial. Given that the government was already resource constrained this strategy would be difficult to adopt. It was further argued that as a stand-alone it would face major challenges related to sustainability. An example was given in Masaka district where funding through UNICEF for TT vaccination came to an end before the girls in the cohort selected for vaccination had completed their immunization. In the circumstances it become the responsibility of the district to look for the funds to complete the doses.

Concern was also expressed that stand alone strategies like projects are usually short-term and there may be conceptual and implementation challenges of transforming the stand alone into an on going program and if not well handled it could be counter productive.

In spite of challenges many stakeholders especially implementers in the district, some parents and teachers, and a few policy makers at the national level considered the stand alone strategy as being the most appropriate strategy for the initial delivery of the cervical cancer vaccine arguing that later when the vaccine has been tested, tried, found effective, and accepted, then it can be integrated in other strategies such as the Child Days Plus.

5.2.2 Child Days Plus Strategy

The Child Days Plus Strategy was another strategy suggested as being appropriate for the delivery of the HPV vaccine to girls aged 10 to 12 years both in and out of school. The Child Days Plus strategy delivers an integrated package of preventative services twice a year for the duration of a month with the objective of reaching high coverage and reducing inequities in health care. Child Days in Uganda are conducted in April and October each year. During the Child Days health services are delivered to children through schools and through other out-reach centers including churches, community centers, Local Council offices and at all health units. A review conducted of the Child Days Plus Strategy in 2006 found that the strategy covered a wide population of children both in and out of school. Furthermore the review noted that in addition to the normal immunization services the strategy also delivered vitamin A supplementation and de-wormed children.

While most policy makers at the national level and some district level respondents were of the view that the HPV vaccine could be integrated with all others vaccines and delivered as part of the Child Days, some district level implementers argued that Child Days were already overloaded with many activities and adding the HPV vaccine to them could compromise the quality of service delivery.

Using Child Days Plus is feasible using it would reduce the disturbance of all those people and institutions involved; and for this to succeed, more mobilization must start well in time before the Child Days…. keeping in mind that CDP is already loaded. There will also be need to train and re-orient health workers so that they appreciate the new vaccine; that should be planned to come with some additional resources. Alternatively, we can off-load some tasks from the Child Days Plus Strategy _ instead of having it twice a year, could do it once a year District Health Officer, Mbarara

Others felt however that adding the cervical cancer vaccine to the package delivered in Child Days Plus would make the package more comprehensive.

I would prefer the Child Days Plus Strategy because it is cheaper, less disruptive and is held twice a year… introducing the cervical cancer vaccine in Child Days would make it a more comprehensive approach. Originally it was measles, then polio until they were combined. Although it will be loaded, it will be comprehensive. CDP currently has Vitamin A given to children 6 months to 12 years, de-worming given to children above 1 year and up to 15 years. District Health Officer, Masaka

The district health officers also observed that the Child Days Plus Strategy reaches out to the majority of children in school but not all. It was observed that girls still drop out of school in upper primary starting from primary five onwards and these could not be a challenge to reach. They indicated that vaccination coverage in schools would reach approximately 75% of primary school age group. Furthermore it was also observed that while Child Days Plus as a delivery strategy could reach out to the majority of girls in this age group, there was need to also devise an appropriate strategy for reaching out to the out of school girls in this age group to ensure that their parents/guardians were informed about the vaccine and that they support these girls to get vaccinated. The formative research found however that some of the out of schoolgirls might be difficult to reach because they were already employed elsewhere outside of their homes. Whether their employers would encourage them to go for this vaccination would be the challenge.

Those who supported the Child Days Strategy argued that it is well received by most stakeholders and is nationally recognized. It targets both in and out of schools children; it has been tested and has a history of success and most respondents considered it to have contributed to improving immunization coverage; it has wider coverage in the country; comes with resources to support its implementation; roles and responsibilities for each stakeholder are easier to assign and demarcate and are already known and some Child Days Plus outreaches were already being held in schools. It was also emphasized however that effort would need to be put into the timely delivery of all supplies and adequate education and advocacy especially regarding the new vaccine that was to be added to the already existing package.

Several challenges were highlighted with regard to adopting the Child Days Plus Strategy for the delivery of the HPV vaccine. Teachers argued that although the play an active role in the Child Days they were not remunerated for their involvement yet the health workers were paid an allowance. Furthermore school authorities reported that some health workers sometimes carelessly left some of the used supplies such as syringes littered around in the school exposing them to the pupils.

Most policy makers especially at the national level reported that Child Days Plus resource requirements are massive. Furthermore it was noted that while Child Days took place twice a year, the cervical cancer vaccine had three doses and if delivered through the Child Days there would be a mismatch of the second dose. There was also the fear that since Child Days occurred twice a year, there could be a tendency for people to relax and forget about the second dose, meant to occur in between the two scheduled sessions. This it was felt could result in higher missed doses and low coverage in the long run.

In order to address the challenges faced in Child Days Plus, it was recommended by district officials that improvements should be made with respect to availability of logistics, supplies, and allowances for personnel involved. For instance, supplies of the vaccine should be reliable; in the past stock outs have been a big problem hampering immunization services in the districts. Follow-up and support supervision must be carried out to ensure that what the district health team plans is actually being implemented. Also, funding should be provided for support supervision.

It was reported that following good mobilization for Child Days Plus there was increased demand for services in the communities, however, this demand is not always matched by available logistics, especially transport in the districts. As a result district health departments sometimes 'borrow' vehicles from other departments and NGOs for use during Child Health Days. Resources for implementing the strategy therefore need to be increased in order to successfully delivery the full package including the cervical cancer vaccine.

5.2.3 Combining cervical vaccine schedules with TT

Another strategy suggested for the delivery of the cervical cancer vaccine was combining it with the delivery of Tetanus Toxoid. The Ministry of Health through UNEPI, the School Health Program, and in collaboration with the Ministry of Education and Sports has planned to integrate Tetanus Toxoid (TT) immunization into School health programs in an effort to meet the global goals of eliminating maternal and neonatal tetanus by the year 2011. The target populations are non-pregnant women of childbearing age. There is an attempt to institutionalize and integrate school health activities into the district development plans. TT was supposed to be rolled out in a phased manner starting with 10 districts in 2006/2007 Financial Year namely Moroto, Nebbi, Soroti, Pallisa, Busia, Kamuli, Mukono, Wakiso, Lira and Kabarole.

Those who favored the strategy of delivering the cervical cancer vaccine together with the TT argued that both vaccines have similar schedules and to some extent they have a similar target population young girls although the target age group for the cervical cancer vaccine is slightly younger. Another advantage advanced in favor of combining tetanus toxoid and cervical cancer was that it would minimize resources and logistics required. It would be more cost-effective as a strategy in that it would cover more girls using limited resources. It was further argued that the combined delivery of the two vaccines would be advantageous because similar approaches and campaigns would be used for both vaccines.

The majority of respondents argued however that although both vaccines targeted young girls, the target groups were different in that tetanus toxoid is given to girls who are at least 13 years and above while the cervical cancer vaccine is targeting 10-12 year old girls. It was argued that combining the two vaccines would cause confusion amongst parents and the girls. It was further argued that while the majority of girls aged 13 years plus were already in secondary schools those aged 10 to 12 years were in primary schools so there were no advantages in vaccinating the two sets of girls together because in most cases they were not physically located in the same place.

Health workers in the districts argued that combining the two vaccinations in an immunization session would increase the number of target individuals and this would increase their workload due to the increased numbers of girls. It was also argued that Tetanus toxoid vaccination has only recently been introduced in schools and is therefore not yet well established. Introducing yet another new vaccine on top of it was perceived by some to be detrimental to the acceptance of both. While some respondents felt cervical cancer introduction would increase uptake of TT, others felt the TT in school has not yet been fully embraced. It was felt that combining its delivery with that of the cervical cancer vaccine

could result in lower coverage.

The reverse was also perceived to be true. It was reported that Tetanus toxoid (TT) immunization currently faces many challenges. Its coverage is still low estimated at 23.2% for pregnant women and 3.2% for non-pregnant women for 2005/06. Possible reasons suggested for low TT coverage included: non-pregnant women not valuing the immunization services; the School Health Education Project (SHEP) not being active as it was in the past; the perception that TT immunization is only for pregnant women; poor scheduling of TT immunization at times or on days inconvenient for women and general lack of awareness of its benefits. Fear was expressed that uptake of the cervical cancer vaccine could be comprised by similar changes if combined with TT leading to the suggestion that the two vaccines should be delivered separately until these challenges have been addressed.

5.3 Preferred venues for vaccination

Suitable venues mentioned where girls could be vaccinated included: health centers, schools, trading centers and communities.. The majority of stakeholders preferred that the vaccination take place in schools. It was emphasized that the majority of girls in this age group were in school. So vaccinating in schools would reach the majority of girls in this age group. For those out of school it was suggested that out reaches would need to be established in the villages, churches and other community centers nearer to where the out of school girls were located in order to reach out to them with the vaccine. It was suggested that making the vaccine readily available in the health facility was also another way of reaching the out of school girls because this meant that they could go and get vaccinated any time.

5.3.1 Vaccination of girls at School

Regardless of the strategy adopted for vaccine delivery, schools were perceived by the majority of respondents as being the most appropriate venues for vaccination of girls in this age group. Discussions held with girls and officials from the district education and health departments, teachers, head teachers and School Management Committees exploring this very issue. Consultations were also conducted at national level in the Ministries of Education and Health and the general consensus was that schools were the most appropriate venue especially for logistical reasons. Some of the girls felt that they were likely to miss fewer lessons if vaccinated at school and that it would take less time as illustrated by the quotations below extracted from focus group discussions with girls:

I would prefer to be vaccinated at school because if you go to the health unit you have to walk a long way and also wait in line

Being vaccinated in school will take a shorter time because all of us will be receiving the same vaccination unlike at health centers where some are babies

I prefer at school because there are other children also being vaccinated so I will not be afraid

Other reasons advanced in favor of schools as appropriate venues for cervical cancer vaccination were that: they provide a convenient and cheap way to vaccinated girls who are in school thus making it possible to reach a big number of the target group using fewer resources. Another reason advanced was that introducing the cervical cancer vaccination in schools would make it easier to integrate it with other existing EPI activities and vaccinations already being conducted in schools. It was further argued that in some communities, outreach services in schools already exist and finding the girls at school would eases the work of the health workers, they would not have to go around the villages searching for girls in the target age group.

Other reasons advanced were that schools have the infrastructure and teachers to make vaccination sessions a success. Schools have large compounds and open areas that can be designated for vaccination, while teachers can help with mobilization of the girls to be vaccinated and guide the health workers around the school. It was also argued that schools maintain attendance registers, and the pupils are well known to the teachers. This makes it easy to track defaulters through the school registers. It was also argued that schools can control children and the school administration, could ensure that they are vaccinated. Furthermore it was explained that schools present a friendly environment. Pupils are already used to it and feel secure with teachers and their peers.

> *Pupils would feel more comfortable psychologically when vaccinations are carried out in schools, where they know that every body is involved. (FGD, Teachers in Masaka)*

It was also explained that if the schools and the education departments were involved in the planning for the vaccination the school administration and teachers could help inform parents about the vaccine and even reassure them that it is good for their daughters and is safe. In which case parents would be comfortable with the vaccinations being conducted in schools. Another advantage given was that peers in schools could be used to mobilize out of schoolgirls, who could also come to the schools for vaccination.

While schools were perceived as the most appropriate venues for vaccination several challenges were highlighted which included the following: Some head teachers and owners of private schools may resist using their schools for immunization in order to avoid controversy in case parents are not comfortable with the vaccination. Other private schools as previously noted are not yet officially registered and have no licenses yet they have enrolled children. The administrators in these schools distance themselves from district education officials and are therefore less likely to participate in school based vaccination programs. Another challenge highlighted with regard to private schools was that the school administrators would perceive vaccination in school as an interruption and as a waste of time given their tight school program.

Other challenges raised were that most primary schools do not have trained medical personnel such as school nurse to handle adverse effects following immunization (AEFI). This meant that AEFIs would require referral to the nearest health facility. This being a new vaccine most people did not know what to expect. It was also emphasized that vaccination in schools could be misunderstood unless adequate sensitization and mobilization of community leaders, teachers and parents is done. One of the Women's Leaders in Kampala cautioned that:

While I feel that schools are the most appropriate venues for vaccinate girls in this age group, it would be a mistake for health personnel to negotiate with schools about conducting the vaccination without consulting the parents. Parents need to be properly informed and they need to give their consent for their children to be vaccinated. Our children should not be ambushed in school it would only increase suspicion and low acceptance of the vaccine

School administrators and teachers explained that schools strictly follow a school calendar, which is preset by the Ministry of Education and Sports and they preferred that the less disruption of the calendar the better. Concern was expressed that sometimes health workers visit schools for vaccination during examination time when children and teachers are busy with examinations, or when teachers are preparing progressive reports. It was explained that during this time pupils couldn't be easily mobilized for vaccination in schools. It was also reported by some teachers that they sometimes helped in the vaccination process by filling in the vaccination cards, but in some cases they were not sure what the particular immunization session was targeting.

District education departments expressed concern regarding insufficient funding for monitoring immunization activities. They explained that the education department works on a small budget. This limits number of schools that could be monitored closely by district staff for conduct of immunization. As previously noted concern was also expressed by district education officials and the teachers in schools that they did not receive any financial incentive for participating in the vaccination programs in schools all the money was usually paid to health workers.

5.3.2 Suggested improvements

Suggestions made in order to addressed these challenges included the following: there should be careful planning involving all stakeholders at all levels, so that the rollout of cervical cancer vaccination is not rushed, thereby being viewed with suspicion. There is also need for a lot of sensitization and provision of all information related to the vaccine for all the people involved at all levels. Most district implementers complained that the CDP and other campaigns from the national level are usually rushed from the top to bottom and they are given little time for planning.

District education officials observed that education and health departments need to closely work together in order to make vaccination in schools smooth. School administrators suggested that there is need for joint planning at district level so that vaccination days can be reflected in the school calendars and the District Education Officer should send circulars to schools and health sub-district in time to help schools prepare for the exercise. They further suggested that schools could be attached to a nearby health center, the in-charge of which could then liaise with the schools in the area on convenient schedules for vaccination. The key players in the schools would be head teachers, Center Coordinating Tutors (CCTs), science teachers and senior woman teacher. These school staff could then help to sensitize the parents and support the girls during vaccination.

It was also suggested by the education officials that so as not to interfere with school calendars, vaccinations in schools should be carefully scheduled to avoid clashes with key school events such as examinations. Further, consideration should be given to the vaccination schedule so that all the three doses can be administered at the right time during school terms. Several respondents who were mainly teachers and those from the education department in the district suggested holding vaccination sessions in the morning. They further suggested that the vaccinations should best be scheduled in the middle of the term because that would be when all children have reported to school. They reported that children sometimes do not report promptly at the beginning of term, while at the end of the term, the teachers and pupils would be busy with examinations.

School administrators and teachers further emphasized that health workers need to be responsible and clean up after vaccination sessions so as to avoid littering the school compound as has been reported in the past immunization exercises at schools. It was also suggested that the school management committee and teachers could be trained and used to sensitize parents and guardians during PTA meetings and in the community about the importance of girls being vaccinated. Furthermore suggestions were made that funds should be allocated in the education budget for district officials from health and education departments to supervise and monitor immunization activities (at the district and other levels).

Private schools in districts such as Masaka and Kampala were found to have formed an association that brings them together. It was suggested by education officials that where these associations exist the district education office should try and ensure that all private schools are registered and affiliated to the association. This would make it easier to engage private schools in discussions of using them as venues for vaccination and rally them to support girls in their schools to be vaccinated.

5.3.3 Health units as venues for HPV vaccination

Health units are the traditional venues for routine vaccinations. Those that preferred them as venues for administering the HPV vaccination argued that they were well equipped with qualified and experienced staff who can administer vaccines including handling any adverse effects. It was mainly children and parents who indicated that they preferred health units for HPV vaccination. This view was more pronounced in Gulu, Mbarara and Masaka districts. As previously discussed in the case of Gulu this was mainly due to the breakdown of the school system and the majority of people living in internally displaced people's camp. In Mbarara and Masaka it was due to safety concerns and the belief that health units can handle AEFI vaccinations better than schools because of their expertise.

Male parents in Mbarara argued that health units are well equipped with fridges and all the necessary supplies. They were therefore sure that if a girl was vaccinated at a health unit the vaccine would be safe because it would be taken directly from the fridge. They were concerned about the safety of the vaccines that were transported in iceboxes to other venues and whether the right temperature was maintained. They further argued that since the

vaccine was new there was no way of knowing what side effects could arise as a result of it not being kept at the right temperature.

During the focus group discussions girls explained why they would prefer health units for vaccination, among their major reasons were that in health units there were plenty of needles and syringes therefore the changes of them being recycled were slim, they could be accompanied for the vaccination by their parents and they associated health units with being attended too by trained and competent personnel. Below are extracts from the discussions:

> *"I prefer the hospital because if they find that I am suffering from any disease they can give me treatment immediately, I prefer the hospital because it is usually well equipped, I prefer the hospital because they usually take my body temperature to find out how hot I am, I prefer the hospital because there I can go with my mother but at school there are only my friends and teachers (FGD with girls in Mbarara)*

> *"I want to be immunized from a hospital or a dispensary because a hospital has many injections/ needles and they cannot use expired vaccines. If you are immunized from the village they may bring few injections/ needles and use those that they have used on other people, some people in villages do not know how to inject and at school some of the teachers might bring expired vaccines"*)

In Kampala, reasons given for preferring to be vaccinated at health centers included:

At health centers professional/qualified staff vaccinate you,
At school medicine can get finished at schools and they tell you to wait and yet at the hospitals when the medicines get finished, they just get more from the stock at the hospital, there are many medicines.
At health facilities, if the needle breaks in you, they can remove it.

In Soroti, most children preferred to be vaccinated at health units owned by government. They reasoned that clinics and hospitals were not usually crowded and parents would be on hand to comfort them and also check on vaccines to ensure they are not expired. In Gulu, schools, health units/hospitals, and community sites for vaccination were all mentioned by the children as possible sites for similar reasons as elsewhere, but health facilities were most preferred because of safety issues and prompt attention paid in case of side effects and other unforeseen events, while schools were easiest to organize with the help of teachers, and therefore best for children in school if vaccination is handled by skilled or professional

On the whole although health units have some major strength over schools, it was deemed by most stakeholders logistically not possible to have all children go to health units for immunizations. Instead the parents and pupils would be comfortable if trained health personnel who go to schools on the days when vaccination takes place carried out the vaccination.

5.3.4 Vaccination in selected venues in the communities

Other venues suggested as being appropriate for HPV vaccination were those that were community based. These included local village council offices, churches, community centers and other public places in the community. These were perceived to be most appropriate for reaching out to girls out of school. Community leaders suggested that out-of-school girls

could be mobilized at the local councils level one (LC 1) and the women council. LC 1 chairpersons and secretaries for the youth on all local council committees would be vital in identifying or mobilizing these girls. It was further reported that some of these girls belong to drama groups and church groups so they could also be reached with messages through these groups. The use of community-based venues through out reaches was also perceived to be a way of capturing girls who may not be able to afford to travel to health centers.

The challenges of community-based venues were also highlighted. These included lack of manpower to conduct regular outreaches and complete records, difficulties in tracking defaulters or those who miss doses, increased staff workload and transport difficulties in the district, which normally hamper the reliability of outreach programs.

5.3.5 Homes

A few respondents suggested homes as appropriate venues for HPV vaccination. This would involve moving from home to home searching for eligible girls and vaccinating them. Those who suggested it thought that it might be a viable strategy for reaching out of schoolgirls. It was however not popular amongst the majority of respondents. Concerns were raised that targeting girls by moving from one house to another would raise suspicion from parents, who might fear that their girls were immunized to render them sterile. This will reduce acceptance and coverage for the HPV vaccine.

Other reasons given for rejecting homes as venues for HPV vaccination were that girls in this target group might not be at home. Covering all homes in the catchment area of a health unit would be tiring and constraining to the vaccinators. Given the limited manpower at the health unit, this would slow down the rate of vaccinations and in the long run it would not be sustainable. The staff at health units may not be well known to community members and as a result they maybe viewed with suspicion when they go vaccinating from house-to-house.

Other concerns had to do with the cold chain. It was felt that if the vaccinators embarked on home-to-home vaccination it was likely to compromise the cold chain given the frequent opening of the cold boxes. This it was argued would increase vaccine wastage and a lot of resources would be required e.g. time, personnel and funds for transport. Furthermore it was perceived to be time consuming and would tie down health workers to communities thereby leaving health centers understaffed.

5.4 Strategies vaccinating the target age group

The formative research also explored the best strategy for vaccinating girls in this age group. A question that arose was whether girls should be vaccinated according to age or to class. This question was put to various stakeholders including officials in the departments of health and education and the responses to this question reflected both perceived advantages but also the possible challenges inherent in adopting either strategy.

5.4.1 Vaccinating by age

It was observed that if a decision were made to vaccinate girls according to age it would possible to systematically vaccinated girls each year knowing that with each age cohort vaccinated the risk of cervical cancer would be also be systematically reduced. The challenges mentioned however of vaccinating by age included the following: Parents and guardians to date sometimes do not recall the exact years in which their children were born nor do they record the exact dates of birth of their children and as a result it is difficult to establish the exact age of the child. Secondly parents sometimes deliberately withhold their children's age for different reasons. For example it was reported in Mbarara that when UPE was introduced parents especially in rural areas quickly enrolled their children even those who were under age in the process they deliberately lied about their children's age recording that they were older than they really were. Furthermore many children in rural areas are born at home and their births are not recorded and they do not have birth certificates so there age is difficult to verify.

It was pointed out with regard to the HPV vaccine that depending on whether the girls and or their parents want the vaccination or not they could lie about the age. With the older ones reducing their age so they can be vaccinated and the younger ones increasing their age so that they are not vaccinated. So the research noted that there could be challenges in determining the correct age of the girls especially in rural areas. Another challenge highlighted with regard to girls in rural areas was that children enrolled in schools at different ages. Although the government policy is that children should enroll in primary 1 when they are six, others enroll when they are 5, while others enroll when they are older than 6. So if a decision was made to vaccinate 10 year olds for example, they could be found distributed across several classes and this would cause a lot of disruption in all the classes between primary three and five as 10 year olds are selected from each class for vaccination.

5.4.2 Vaccination by class

An alternative strategy discussed was vaccinating by class. The assumption here was that it would be possible to capture the majority of girls in a particular age group in one class and this approach would be less disruptive to schools and easy to implement. Other advantages cited with the use of this approach were that it would be easy to administer since the vaccinator would be choosing only one class in the whole school, there would be no stigmatization since all girls in the class would be vaccinated and it would be easier to estimate the vaccine needs due to an established cohort that receives the vaccines each year.

However several challenges would also arise with this approach including: the big variation in terms of age in the selected classes. This variation was likely to be greater in rural schools than urban ones. Across the country children in urban schools tend to enroll earlier in school, that is either in the year that they are going to be six or when they are already six. Some however enroll when they are five. However there is more homogeneity in terms of age groups in urban schools than in rural schools. In rural schools several challenges were mentioned that included pupils repeating classes due to poor performance, secondly because of the long walking distances sometimes involved children in rural schools tend to start school when they are older. So there is less homogeneity in terms of age in rural schools.

Other challenges highlighted with regard to this approach was that it was felt that the HPV vaccine should be delivered as part of a comprehensive package for the whole school and not as a package for one class alone. Other issues raised had to do with accelerated promotion in which case the child though younger is in a higher classes and if this strategy is adopted they would miss out on the vaccination. Another challenge highlighted was that depending on the school classes being vaccinated might change depending on the age group in each class.

To illustrate the dilemma of age and class data were collected on the distribution of age by class for girls enrolled in primary four to seven in three schools in rural and urban Uganda. The data were collected from one rural school in Mityana district in central Uganda and the two schools in Kampala that were visited during the fieldwork. Although Mityana district was not one of the original schools visited during fieldwork, it is a typical rural setting similar to other districts studied.

Fig 5.1 Mean Age by Class distribution of Girls in Sekanyonyi C/U Mixed Government Primary School in Rural Mityana District

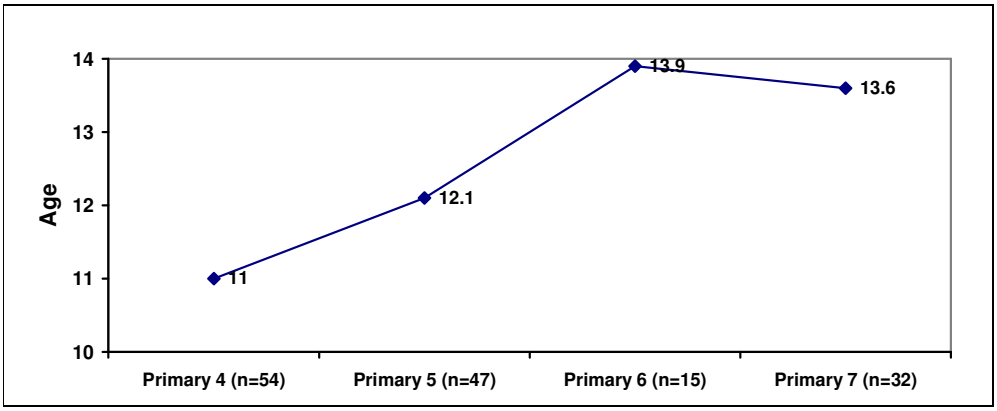
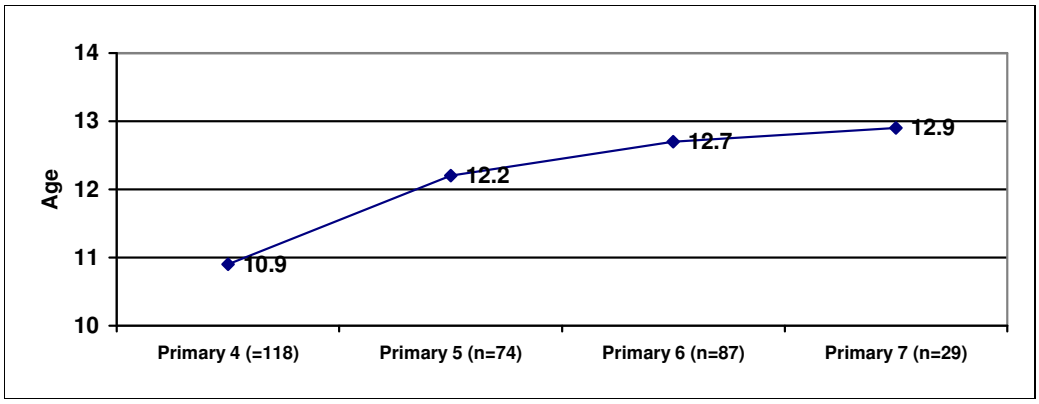


Figure 2 shows that in a typical rural area the average age for girls in primary five is 12.1 years implying that taking primary five one misses the 10-12 year olds. This age is slightly higher than the target age of 10 to 12 years.

Fig 5.2 Mean Age by Class distribution of Girls in St James Biina Mixed Private Primary School in Kampala District



Data presented in Figure 3 is from a peri-urban school in Kampala. Here again the average age of girls in Primary five was 12.2 years

Fig 5.3: Mean Age by Class distribution of Girls in Kalinaabiri Mixed Government Primary School in Kampala District

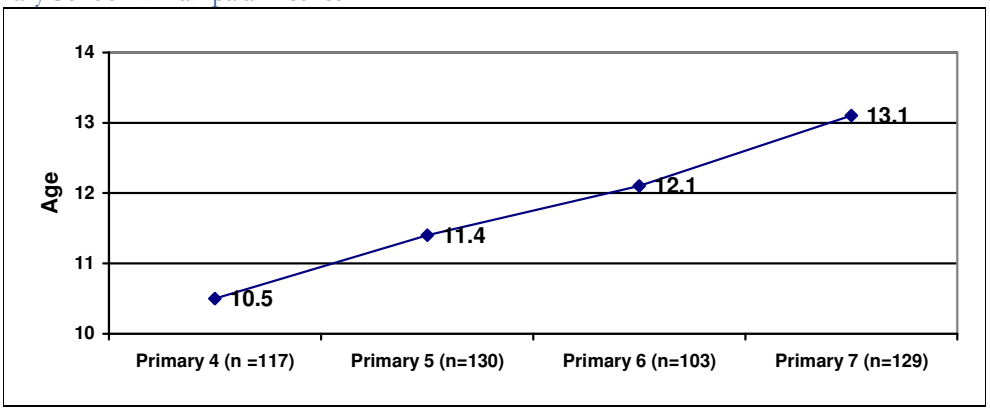


Figure 4 presents data from an urban school. The data shows that on average girls were 11.4 years. The Figure also shows that the target population in Kampala is mainly between primary four and five. The data from the three schools suggests that if one is to target girls 10-12 years in rural areas and peri –urban schools the best class to vaccinate would be either primary three or four. In urban areas it is primary four or five.

5.5 Best period to carry out vaccination in schools

It was suggested by the majority of stakeholders that when vaccinating in schools the health team should consider the school calendar so that they don't deliver the vaccine during

examination period, holidays, or any other times when schools are busy. Officials from the education departments suggested that the vaccinators could choose one day in a week e.g. Wednesday to deliver the vaccine. With regard to the months for the vaccination, stakeholders suggested to have the first dose in April (to coincide with Child Days), the second dose in May, and the third dose in October (to coincide with Child Days). This fits into the vaccination schedules of 0, 1, and 6 months.

It was also suggested that the vaccination should avoid spillover to the next year since some pupils change schools at the end of the year. Similarly the vaccination should not be done at the beginning of term because many pupils would not have reported by then. It may be done at least one month into the school term.

The research found no health services specifically designed for children aged 10-12 years although there were some existing strategies through which this particular age group was reached with specific health services. Most noteworthy among the strategies was the Child Days Plus. Others were different forms of outreaches that reached out to children both in schools and communities. There was general recognition that the majority of the target age group are in school (75%) thus suggesting that a school based strategy would be an appropriate option with outreaches to reach girls out of school. An alternative strategy proposed was the delivery of the Cervical Cancer (HPV) Vaccine as a stand-alone project. While there was general acknowledgement that each of the proposed strategies has strengths and weaknesses, the majority of stakeholders argued that it would be cheaper and more cost effective if the vaccine was integrated into already ongoing programs rather than be introduced as a stand-alone. It was also argued that its integration into already existing strategies would in the long run ensure its sustainability.

Schools were perceived to be the most appropriate sites for vaccinating girls in this age group supplemented by outreach centers for vaccinating girls out of school. A major concern for the school administrators however was that when health workers used their schools for vaccinations they sometimes left used syringes, needles, and other supplies litter all over the compounds which puts the lives of the children at risk. Secondly they requested for joint planning with the health departments so that they could factor into their school calendars and programs the proposed vaccination days. There were complaints that sometimes health workers just turned up at schools without prior warning and planning. Finally concerns were expressed that while teachers were sometimes used to help with the vaccination process no allowances were paid to them for the extra work that they did. Both parents and teachers expressed concern about the fact that schools could not handle adverse effect that may occur after the vaccination. They argued that this being a new vaccine the after effects were not yet known. This is issue that should be carefully handled during the training. Failure to do so could cause serious credibility problems.

The issue of whether children should be vaccinated by age or class remained unresolved and needs further exploration. The findings suggest however that which ever strategy is adopted the rural/urban dimension cannot be ignored.

6.0 COLD CHAIN AND LOGISTICS MANAGEMENT

Since 1983, the vaccine delivery system in the public domain in Uganda is overseen by the Uganda National Expanded Program on Immunization (UNEPI) on behalf of the Ministry of Health. It is the mandate of UNEPI to provide potent, safe and effective vaccines for all children and women of child bearing age in Uganda. The EPI Policy and UNEPI Standards (December 2003) provide guidelines for planning, management, implementation and monitoring of immunization services at National, District, Health Sub-District (HSD) and lower health facilities. Given that 40% of EPI routine activities are entirely a cold chain and logistics affair, effective cold chain and logistics management were perceived to be critical to the introduction of the HPV vaccine. As part of the vaccine delivery component, the formative research assessed cold chain and logistics management both at national and district level.

The objective of this aspect of the research was to collect and analyze data on the vaccine delivery systems in UNEPI at both national, district and health unit level in view of identifying needs specific to the HPV vaccine introduction into the routine immunization service delivery of UNEPI. The issues explored included:

- Current cold chain and logistics practices favorable for HPV vaccine introduction
- Volume/storage capacity gaps existing at the National, District and Health Unit that may hinder the introduction of the HPV vaccine
- Gaps identified at the different levels that need to be bridged before the introduction of the HPV vaccine?
- Frequency of distribution of vaccines and other supplies to the districts and Health Units that will ensure a minimum cost implications and interruption of the availability of vaccines and other supplies for the delivery of immunization services?
- Staffing needs arising as a result of HPV vaccine introduction

6.1 Conditions found to be favorable for the HPV vaccine introduction

The following conditions were found to be favorable for the introduction of CCV into the routine immunization service delivery; all refrigerators used to store vaccines are set to keep storage temperatures from +2°C to +8°C. This is the same temperature range that is recommended for the storage of CCV. Refrigerator temperatures are routinely monitored. As a policy refrigerator temperatures are read twice daily irrespective of whatever day of the week or month or year. Freeze watches are used especially at the central vaccine store (CVS) and there are also available in a few districts. This vaccine management tool is used to monitor freezing conditions. The policy guideline provides for the keeping of vaccines at the district and H/U for only a period of one month but at most six weeks and replenishment of the vaccines is on monthly basis this helps in reducing vaccine wastages. UNEPI already has experience in storing vaccines in the less cold part of the fridge to avoid freezing and the use of the First Expiry First Out (FEFO) and First In First Out (FIFO) methods in issuing vaccines helps to avoid vaccines expiring in the fridge. Conditioned icepacks are used for packing and transportation of vaccines and all vaccines and injection materials are recorded

in the Vaccines and Injection materials control book (VIMCB) every time there are any transactions.

6.2 Cold Chain Management

At the central level the research found that there are two cold rooms that are used for the storage of DTP-HepB+Hib, TT and BCG vaccines at +2°C to +8°C with vaccine storage capacity of 38,706 liters. There are two standby generators to run the cold rooms when the main grid line electricity is off. Vaccines and injection supplies are procured through UNICEF and shipped on quarterly and half yearly basis respectively. Import certificates are obtained from NDA before the vaccines and the Ministry of Health pre-qualified clearing agents clear the supplies. Adequate quantities of distribution equipment like the cold boxes and icepacks are available. UNEPI has seven (7) delivery trucks for the distribution of vaccines and supplies to the districts although three (3) are old and need replacement. Deliveries of the supplies are made monthly to the districts. There are five cold chain technicians available to provide maintenance on the equipment and four vaccine logisticians responsible for the receipt, management and distribution of vaccines.

At district level the study found that the district vaccine stores have both the electric and gas operated refrigerators for storage of vaccines at +2°C to +8°C. At least every Sub County in the districts visited has a refrigerator for the storage of vaccines. All the units visited recorded temperatures between +2°C to +8°C and temperature recording was done twice daily. There were adequate quantities of vaccine distribution equipment like the cold boxes, vaccine carriers and icepacks at the district and in the units. Occasionally power outages occur mainly due to lack of gas but the health workers reported that they promptly transfer the vaccines to another refrigerator in another unit. Vaccines and injection materials are distributed monthly to the Health Sub Districts (HSD) by the district except for Kampala where the units collect their supplies from the district vaccine store (DVS). Some units collect vaccines on bi-weekly basis from either the HSD or the DVS. Apart from Kampala district, all the other districts have vehicles that can be used in an integrated manner to deliver vaccines to the units.

All the districts visited have district cold chain assistants (DCCA) who manage the cold chain with some other persons available to support them. However, for Kampala, the DCCA only manages the equipment but not the vaccines hence leaving a gap in vaccine management in the district store. All the units visited have more than two trained health workers who can provide immunization services. This number of staff is presumed adequate for the delivery of the cervical cancer vaccination

6.3 Cold chain storage gaps and possible solutions for bridging the gaps

Although there are two cold rooms, which store vaccines at a temperature range of +2°C to +8°C, there is no capacity to accommodate the HPV vaccine at the peak of quarterly vaccine receipts as illustrated below.

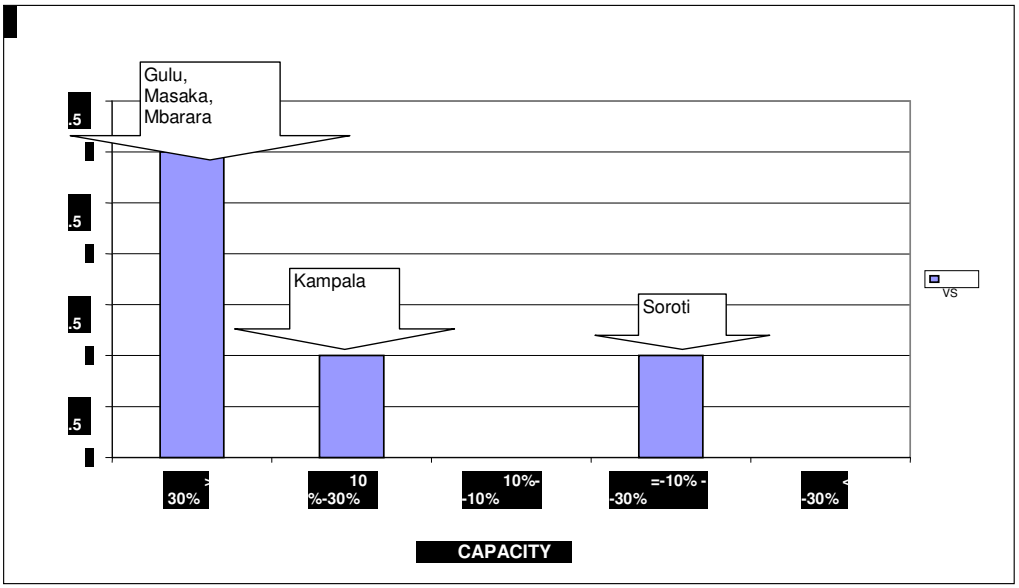
- National cold storage space available 38,706Lts
- Required space for routine vaccine storage 37,106Lts

- Storage space required for CCV for the 5 districts 2,451Lts
- Storage space required for CCV for the country 20,025Lts

Following from the above figures, there is a gap of 851lts of storage space if the piloting is to be done in the 5 districts and 18,425Lts if there is a roll out of the CCV in the whole country. As a suggested solution, the following should be taken into consideration when piloting and/or rolling out the HPV exercise. If the piloting does not cover all the 5 districts and is concentrated in one or two districts, then there will not be any significant storage gap to be addressed. This can be accommodated within the existing capacity. However if all the 5 districts are considered for piloting the HPV vaccine then an additional 5 Ice lined refrigerators are required before the start of the pilot project. In case of a roll out of the HPV vaccine in the whole country, then a cold room with a storage capacity of not less than 25,000 Liters needs to be installed.

At district level the storage capacity for both CCV and routine vaccine in the 4 district stores of Kampala, Gulu, Masaka and Mbarara are adequate. Apart from Kampala, the other three districts have storage capacity in excess of 30%. For Soroti district, the capacity is not adequate by 36.02Lts of vaccine storage space. However although the four districts have adequate space, Gulu, Mbarara and Masaka have excess storage space and can ably accommodate the HPV vaccine and routine vaccines for the next 10 years while Kampala's capacity would need to be revisited in 5 years. Soroti DVS would need a V170GE Sibir fridge to increase the capacity to store vaccines. Prior to any roll of the HPV vaccine individual district vaccine store capacities would need to be assessed.

Figure 6.1 Comparison of district vaccine stores



At sub county level an assessment of each health unit for its capacity to store for the catchment's population was not possible as the population per health unit was not readily available. Therefore, total number of units in a Sub County was aggregated for the establishment of storage capacities at Sub County level as population figures were readily available. Of the 73 Sub counties in the five districts, only 5 of them were established not to have adequate storage capacity if the HPV vaccine is to be introduced. Table 3 shows the districts and the sub counties in which the capacities are not adequate and there respective storage gap deficits.

Table 6.1: Sub Counties with inadequate storage capacity

No	District	Sub County	Volume gap (Lts)
1	Soroti	Arapai	6.00
2	Soroti	Kamuda	4.94
3	Mbarara	Kashongi	11.55
4	Gulu	Layibi	12.40
5	Gulu	Pece	26.32

Possible solutions to the gaps mentioned included the need to purchase the following fridges, 2 RCW42EG for Arapai and Kamuda, 2 V110GE for Kashongi and Layibi and 1 V170GE for Pece. In the event of roll out of the HPV vaccine, the rest of the Sub Counties capacities would also need to be assessed.

6.3.1 Cold chain management challenges

One of the key cold chain management challenges found was the retention of gas cylinder for running the refrigerators in the face of power shortages in the country. There maybe the temptation to use the gas when there is no electricity and forget about vaccine storage as a priority. The second challenge was the shortage of gas, which is used to run 80% of the refrigerators in the immunization program. This affects cold chain management. Shortage of gas sometimes results in units suspending provision of immunization services. The third challenge is that of piloting in a small area, lower than a district level. In the event of acceptance of the vaccination, the demand may outstrip the supply. These issues will need to be taken into considerations as preparations are made for piloting the HPV vaccinations in the districts.

6.4 Logistics

In assessing logistical needs for the introduction of the cervical cancer vaccine, it was noted that there would be need for adequate quantities of the vaccines and supplies in order to avoid stock outs or over stocking. Therefore appropriate working figures will be very essential in the estimation of supplies.

6.4.1 Fuel Source for refrigerators

The research found that 80% of the refrigerators used to store routine vaccines in Uganda use Low Pressure Gas (LPG) for their operation with each fridge provided with two gas cylinders. The gas distribution to the districts is carried out on a monthly basis. It was reported that with the rampant loss of gas cylinders, there is a shortage of gas cylinders in the districts making it difficult to manage the cold chain. This results in high vaccine wastage.

The assessment found that 28% of the cylinders in the 5 districts (representing a total of 129 out of 460 cylinders) were missing thereby posing a cold chain risk to the introduction of the HPV vaccine. The individual district cylinder gaps are as shown in figure 3 with Kampala district being the most affected. The solution to the lack of adequate cylinders is to purchase new ones in order to improve on cold chain management. Given these circumstances it would be important prior to the demonstration project to first establish the numbers of cylinder required to effectively manage the cold chain.

Table 6.2 Gas Cylinder Gaps

No	District	Expected Quantity	Available Quantity	Gas Cylinder Gap	%age of the gap
1	Soroti	60	38	22	37%
2	Masaka	122	105	17	14%
3	Kampala	126	52	74	59%
4	Mbarara	56	42	14	25%
5	Gulu	96	94	2	2%
	Total	460	331	129	28%

6.4.2 Staffing needs

All the districts visited have district cold chain assistants (DCCA) who manage the cold chain with some other persons available to support them. However, for Kampala, the DCCA only manages the equipment but not the vaccines hence leaving a gap in vaccine management in the district store. All the units visited have more than two trained health workers who can provide immunization services. This number of staff is presumed adequate for the delivery of the cervical cancer vaccination.

To improve on the manpower for vaccine management, Kampala should be decentralized to the divisional level such that each division is responsible for their storage and distribution of vaccines and immunization supplies. This will also improve on the transport problem, as each division will use their divisional transport means for distribution.

At UNEPI, there is need to assign a specific person to handle the HPV vaccine such that all the lessons learnt both at the center and within the districts are properly documented. There is need to orient all health workers on the importance of cervical cancer vaccination so as to enlist their effort towards this noble cause.

6.4.3 other gaps identified

Transportation was identified as a gap in some of the districts. While some have at least a vehicle for the distribution of immunization supplies in an integrated manner, Kampala district did not and this needs to be addressed. Fridges were another concern. Although some fridges were counted among those available at the sub county level, some of these fridges were not working and require repair. These include 4 solar fridges and 3 sibirs. The worst hit district is Soroti with 5 faulty fridges, one in Masaka and one in Mbarara.

Freezing capacity for the provision of icepacks for maintaining cold chain during outreach sessions including schools is inadequate. This is as a result of the type of fridges in use at the units, which only freeze four icepacks in 2 days. This means that only three sets of icepacks are available for use in face of the increased demand for reaching every school on top of the routine outreaches. Districts and HCIV should freeze icepacks and transport them to support units during the month of the implementation of the HPV vaccination. Districts should be supported with funds to enable them to distribute vaccines and pay health workers timely.

6.4.4 Delivery Schedule

UNEPI receives vaccines and injection materials on quarterly and biannual basis respectively. These are in the months of January, April, July and October for vaccines and January and July for injection materials. Therefore the months of March, June, September and December are the months when the quantities of vaccines in the cold rooms are at the lowest level. These are the months that could be the best for the receipt of the HPV vaccines. But consideration should be given to the months of implementation of the vaccination such that vaccines should be in store two months to the designated period so as to allow for the distribution to the lower health units. It is recommended that vaccine be received in three consignments during the period piloting the introduction of HPV.

For the injection materials, the months in which to receive the injection materials do not matter but must relate to the period of the vaccination. Therefore it would be good to receive the injection materials two months before the stipulated months for the vaccination exercise against cervical cancer to start. This will allow for distribution to the lower level early enough for implementation not to be disrupted. Two consignments are required to be delivered. The first consignment should be 70% of the entire quantity required in a year. The storage capacity at the unit level was estimated at monthly requirements as stipulated in the policy and hence the deliveries to the districts are expected to be on monthly basis.

6.5 Updating existing record keeping system to cater for the new vaccine

The formative research assumed that the record keeping system for HPV vaccine will most likely be integrated into the existing EPI system, which is part of the MOH HMIS system. The research found that Health units maintain child registers. Child health cards and TT vaccination cards are also used but these are issued and kept by the clients. Health units send report forms to the district where HMIS summary forms are made and kept in the district database.

Stakeholders interviewed felt that the fewer the documentation tools the better. This will lessen paperwork and improve data collection on the vaccine. In their opinion, the existing records system is adequate, but might require a few modifications to accommodate HPV vaccine. It was further suggested that cervical cancer vaccination registers could be kept both at the school and health centre. Science teachers, senior woman teachers and head teachers could keep these vaccination records in schools. It would be important however for record keeping purposes for the health units conducting outreach in the schools to maintain a copy since it would be needed to produce monthly reports for the district. The research found that the existing tally sheets and summary sheets could also be modified by adding sections to cater for cervical cancer vaccination. This can be done through UNEPI and MOH.

For purpose of documenting individual cervical vaccine vaccinations, the research found that the TT card was preferable for several reasons: It is used for people aged above 5 years. Mothers tend to lose the child health cards once their children are through with immunization for under-5 year vaccines, TT target begins from 13-14 years, hence making a card that combines HPV vaccine and TT logical since girls vaccinated against cervical cancer will soon be eligible for TT. They are also more likely to keep their cards up to the time (a year or two after cervical cancer vaccination) when they know that it will be needed for TT. If these two programs (TT and cervical cancer) are designed as longer-term national programs then a girl may have one card to use for cervical cancer when she is 10-12 years, and tetanus toxoid when she is 13 years and above. The two have similar schedules thus making it easier for the TT card to be modified by adding a section to cater for the HPV vaccine schedule of 0, 1 and 6, which is similar to the first 3 TT doses. Alternatively, the back of the TT card could be used to capture HPV vaccine data. TT cards are already in the process of being modified for the school health TT program.

Since the long-term plan if adopted would be to integrate the HPV vaccine into the routine EPI programs the HMIS mode would be the best system for reporting cervical cancer vaccinations since it provides for monthly reporting and summaries. The campaign mode of reporting is occasional and rare, hence providing infrequent data to meet regulatory and monitoring needs.

6.6 Handling and Monitoring Adverse effects following immunization (AEFIs)

The HPV vaccine is a new vaccine and the research explored the current handling and monitoring of adverse effects following immunization. The research noted that there can be several types of AEFIs:

- Vaccine reaction (due to inherent vaccine properties)
- Programme error (error in vaccine preparation, handling or administration)
- Coincidental event (chance association)
- Injection reaction (including anxiety-related, injection pain)
- Unknown

Various stakeholders emphasized the importance of monitor AEFIs for HPV vaccine because it is a new product and no vaccine is 100% safe. Caution was expressed that improper management of AEFIs could cause negative publicity resulting in low levels of

acceptance of HPV vaccine. It was recommended therefore that prompt and proper resolution of AEFI would enhance public confidence in the immunization programs.

Mitigation of negative publicity attributed to AEFIs was also reported to be very crucial. A classic example was the death of a child following immunization occurred in Bukulula health centre in Masaka in 2003. It was widely publicized and had a negative effect on immunization in this district. The district officials had to explain to the population what exactly happened. Even officials from the Ministry of Health went to investigate what happened and explain to the population. It was later discovered that the incident was not related to immunization. The case concerned a mother who took a set of twins to the health unit to be immunized. Thereafter, when she went home, she got drunk and accidentally suffocated to death one of the babies. To cover up the mess, she attributed the death to immunization. When the team from the Ministry of Health came, it found that the batch dispatched had no problems and the second twin was fine.

Therefore, given that this is a new vaccine, all safety concerns should be looked into seriously. Otherwise, any problem related to the vaccine will affect all other programs in the district. The research found that the current EPI system, AEFI management encompasses:

- Detection
- Reporting
- Investigation
- Management/Resolution
- Document

The process currently in used was described as follows: AEFIs are identified during immunization or reported to health centers by parents. Health workers detect and report AEFIs to EPI Surveillance Officers at respective health sub-district, who do the follow up of the AEFIs. The EPI Surveillance Officers in conjunction with District Health Visitor or EPI Focal Person investigate and where possible take specimens, which are then sent to UVRI for testing. Reported AEFIs are managed according to outcome of investigation.

The research found the existing AEFI data management forms sufficient. Several AEFI monitoring forms are used to capture and report AEFIs. Forms used include HMIS No., Rapid Convenience Survey Tool, and the newly introduced National Drug Authority Adverse Event Reporting Form. The latter is in the process of being harmonized and adopted for general use for reporting all adverse events related to medicines and vaccines. Besides the existing systems for identifying and reporting AEFIs, effective monitoring for HPV vaccine-related AEFIs will require:

- Adequate sensitization
- Targeted distribution of IEC materials
- Having drugs (e.g. antihistamines) handy for managing AEFIs, just in case unexpected adverse effects occur

UNEPI has the cold chain structures on the ground that can comfortably be used for the delivery of the HPV vaccine to the targeted population throughout the country. However, in the event of rolling out, the storage at the national level should first be addressed and also

cold chain assessment be carried out in the areas designated for the roll out. Therefore, whether it is piloting or rolling out, UNEPI should be involved at every stage.

Adequate sensitization and mobilization must precede the introduction of the vaccine. Good care must be taken of the AEFIs monitoring, Record keeping, Logistics, and School data during the demonstration project.

7.0 FINDINGS: POLICY COMPONENT

7.1 Introduction

This section presents findings for the policy component of the study; which was designed to generate information regarding the current health policies, the policy environment, and processes relevant to policy formulation for vaccine introduction and adoption. Data was collected from a cross section of policy and decision makers at various levels and key sectors, program mangers and district officials- technical as well as political. The findings are presented along major themes, with subsections addressing critical policy issues, concerns and recommendations regarding HPV vaccination program.

Health policy is a 'vehicle' for creating supportive environments to enable people to lead healthy lives. As new technology such as vaccine becomes possible and available for prevention of cervical cancer, policy-making decisions and processes become a key phase in the introduction of the new vaccine in the country (WHO, 2005). Cervical cancer vaccine (HPV) is intended for pre-adolescents, and this is likely to present challenges in prioritization and investing into the intervention. Rational arguments need to be put to the decision makers to convince all that such investment is worth, given the severe government budgetary constraints in the health sector.

As part of the formative research, it is essential to explore how health problems and vaccines become priorities and how health priorities are determined and by whom. These include factors that are considered and criteria used in reaching decisions on new vaccine programs, strategies identified for implementation and types of data most critical to guide decision-making for introduction of HPV.

7.2 Objective

This component of the study was designed to review the relevant health policy environment, mapping key stakeholders in the decision making processes and identifying critical issues important to national decision making about cervical cancer prevention services including vaccine adoption.

7.2.1 Specific objectives

- Assess the present policies and processes of their formulation that are relevant in the introduction of cervical cancer vaccine
- Establish and map out key stakeholders and 'champions' driving the key policies relevant to cervical cancer and how this data (from the survey) can be disseminated most effectively to them to translate into policy decisions.
- Identify critical issues to inform, leverage and support cervical cancer vaccines introduction plans in the country

7.3 Viability of Current Health Policies and Programs

7.3.1 A range of relevant policies and programs

A whole range of policies and programs exist in health service provision that can accommodate vaccination against HPV to prevent cancer of cervix (Table7.1). This component presents an analysis of key policies and strategies that might be relevant for introduction of HPV vaccination as a means to prevent cervical cancer. In this section critical issues and processes for formulation and implementation, are discussed.

The following policies and strategies were reviewed to bring out the opportunities, gaps or limitations for introducing the HPV vaccine and make suggestions for appropriate actions.

- National Health Policy and Health Sector Strategic Plan II
- A strategy to Improve RH in Uganda
- National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights
- UNEPI policy
- School Health Policy

National Health policy and Health Sector Strategic Plan II

The overall goal of the National Health Policy (NHP) is to reduce mortality, morbidity and fertility and the disparities therein. The Health Sector Strategic Plan II (HSSP II) implements the NHP by ensuring access to the Uganda Minimum Health Care Package UMHCP).

Within the HPPS II, there are plans to quantify the burden of non-communicable diseases disease (NCDs), which include cancers as well as sensitizing the population on these diseases. This offers an opportunity to quantify the burden of disease due to cancer cervix and use the opportunity to sensitize the population on the magnitude and programs for reducing the problem. Furthermore the NCD policy is in the offing and could include provision of a comprehensive package for prevention, screening and treatment of cancer cervix. The ongoing plans for revamping secondary prevention of cancer cervix by building capacity of regional hospitals offers another opening for offering support to these hospitals to offer comprehensive package of services.

Prevention of cancer cervix embraces the objectives of enhancing gender and equity issues in service provision within the HSSP II, while promotion of immunization that is a key priority in HSSP, can be built on when introducing HPV vaccine. At the community level, the promotion of the Village Health Teams (VHTs) is put forward as an effective vehicle for mobilization and reaching out to the community and households for health interventions. This is a potential strategy to mobilize and promote the HPV vaccination in communities, giving the information to communities and households.

The main limitation of HSSP II is narrow focus and view taken by the Sexual and Reproductive Health within, which is limited to emergency obstetric care for the current period while the focus on cancer is general with no specific prioritization of cancer cervix. In

addition to that, the cancer cervix prevention has not included vaccination and the process of operationalizing of VHT has been greatly constrained by limited resources.

Policy implications for HSSP II therefore include broadening the sexual reproductive health focus to prevent cancer cervix by offering HPV vaccination, reviewing the Reproductive Health policy to emphasize primary prevention of cancer cervix and listing HPV vaccination among the immunizable conditions. As the VHT strategy is expanded in the country, information on burden of cancer cervix and its prevention could be included.

Strategy to improve RH in Uganda (2005-10)

The goal for Strategy to improve RH is to offer improved access to RH services, including family planning and emergency obstetric care. The strategy uses Health Management Information System (HMIS) and survey data to make decisions for service provision and this offers the opportunity collecting require data on cancer cervix for evidence-based planning. Within this strategy, collaboration with private sector, CBO is emphasized to strengthen community participation in RH, a means that can be used to provide partnership if HPV vaccination is introduced. Improved links to community through the VHT mechanism, offers another opportunity for mobilization for wide community participation in the intervention. The main limitation is that the minimum package of priority activities to improve RH provided in the strategy does not include cervical prevention through vaccination, an addition that may be required in introducing HPV vaccination.

National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights (2006)

Goal for these guidelines and service standards is to improve SRHR for all through provision quality accessible and equitable RHS. Unlike HSSP II, broader definition of SRHR includes RH cancers, offering better prospect of inclusion of HPV vaccination as a means to prevent cervical cancer. The Standards underscore offering comprehensive package for cervical cancer services, paving the way for possibility of including primary prevention. Currently regional hospitals are equipped for cervical cancer screening services, a mandated that can be expanded collecting data on cervical cancer. The service standards provide for strong element for community outreach, another opportunity to reach out to adolescent girls out of school, should vaccination against HPV be introduced.

The main gaps are the facility-based RH cancer services are limited to screening and treatment of cervical cancer while the lack of emphasis on data collection in outreach services, hampers the realization of the burden of disease due cervical cancer.

UNEPI policy

The UNEPI policy is intended to achieve full immunization coverage against the listed vaccine preventable diseases. It has the flexibility to include vaccination of additional high burden diseases and target the appropriate groups. This offers an opportune entry point for possible new vaccines such as HPV vaccine. The policy provides for booster dozes for TT to children at 5 years or more in and those out of school, another opening for introducing HPV vaccine. EPI program has relevant infra structure and operational structures in place and can support and accommodate new vaccine. Furthermore EPI has the social mobilization countrywide and has recorded success that can be built on.

The main limitation to integrating HPV vaccine in EPI program is the mismatch in target age; HPV vaccine targets 10-12 years, while EPI targets under-fives and women of childbearing age (15-49 years). Another potential huddle is the low staffing levels that deliver EPI vaccines, an additional vaccine may easily overload the system. The information on cancer cervix is still be included into social mobilizations for EPI program. Policy implications of UNEPi policy mainly dwell on reviewing the policy to include HPV vaccine to prevent cancer cervix, and expanding the immunization target group to include 10-12 years old girls.

School Health Policy

The goal of the School Health Policy is to improve health status of school children including catering for different gender needs. Already there is functional collaboration between the MoH and MoES in service delivery in schools, offering a unique opportunity for two ministries collaborate on HPV vaccination program. The MoES is currently developing school health strategy, a strong possibility including HPV vaccination in schools in the strategy. Within the School Health Program, advocacy, capacity building & sensitisation of schools at all levels is possible and integration of HPV vaccine is possible when the school TT immunization is rolled out in districts.

The main gaps in School Health Policy are the absence of cancer intervention and the exclusion of girls not in school. A special strategy to reach girls out school would be required, probably through outreach health services.

7.4 Critical Issues and Policy Making Process

7.4.1 Relevance for Introducing Policy for Vaccine for HPV

The first concern investigated was whether introducing HPV vaccine would require a policy in Uganda. Stakeholders at national and district levels were interviewed to find out if there was need for a policy. At the national level, policy makers reported that in principle a policy or policy guidelines were necessary for introduction and implementation of a new vaccine- HPV vaccine, and they gave several reasons for this.

Government Commitment and Endorsement of Vaccine

The policy, they stated was essential as a means to informing high authorities, engaging their commitment and actively keeping them involved in providing support for the process of introducing HPV vaccine. It was also widely felt that if a policy on HPV vaccine were in place, this would be some form of government endorsement for the intervention, reassuring the public that the vaccine is safe and necessary. This, they said, was important for dispelling fears and suspicion likely to arise among the people as the vaccine was to be given only girls at beginning of their reproductive career. The policy, they added, would provide legal and regulatory framework and would help planners to prioritize the intervention and mainstream it into on going programs.

"The starting point for any new intervention is a policy and strategic plan that provides a framework for the action" senior planner MoH

Inform Key Actors and Public

The process of developing a policy, it was stated, would inform the public at large on the need for vaccination as a means of preventing cancer of cervix, a hidden problem on which the public has very little information as compared to other vaccine-preventable conditions, such as measles and polio. The policy and the process of its formation would guide and inform all actors and players including service providers, of their various roles in implementing the intervention. The policy would also indicate cost implications and operational costs, logistics and capacities including procurement and distribution of the vaccine.

7.4.2 Type and Nature of Policy needed

Many top policy makers in the MoH and other sectors such Education and Sports and Ministry of Gender interviewed agreed that there was no need for a separate policy, but policy guidelines were enough to prioritize the intervention for implementation.

> "The danger of coming up with a new policy is that health workers will be tired of them. At the moment I think we have over 150 policies" Assistant Commissioner MoH.

When asked to comment on whether a HPV vaccine policy should stand on its own, policy makers and implementers strongly felt that it should be integrated into the Reproductive Health (RH) Policy and Plans. Districts planners were in agreement that the HPV vaccine component should be integrated into already existing MoH plans (HSSP II), ideally as part of RH policy. They noted that the current RH policy highlights several key areas of reproductive health to be implemented in the next 10 years. Although the current RH policy guidelines provide for screening of cancer of cervix, they do not provide for its primary prevention. They suggested that RH guidelines should be reviewed to integrate HPV vaccination for prevention of cancer of cervix.

Regulation for HPV Policy

Majority of policy makers interviewed felt that this policy did not require parliamentary approval or a bill/law. They noted that vaccinating girls to prevent cervical cancer is health service delivery and normally people are not coerced to utilize health services but are convinced when adequately informed.

> "*It does not need to be law because it means it would become mandatory. We are just going to persuade people to take the vaccine" MoH Policy Advisor*

Acts in the health sector are often passed to enforce mandatory public actions such as the Public Health Act of Parliament and the Drug Law. Respondents mentioned that rarely has vaccination been made mandatory, such as in cases where an immunizable disease is disappearing and users are less motivated to turn up for services. They gave an example where parents were required to show proof that a child had completed the primary set of immunization on admission to primary school. Some district officials interviewed were of the view that once HPV vaccine was introduced and it makes some positive impact, it should be made mandatory for all girls in upper primary as a long-term solution to control cervical

cancer. In the meantime the overall consensus was that cancer cervix should be considered as any one of the immunizable diseases and the HPV vaccine should be included in the traditional vaccinations.

7.4.3 Policy Prioritization: factors and process

On inquiring as to what factors policy makers consider during prioritization of health issues for policy, it was evident that new policies are often considered in context of existing ones. They noted that for example, the National Health Policy spells out what should be done under its components of maternal health, disease control, and poverty eradication. Prevention of cancer cervix addresses all these concerns, and therefore HPV vaccine policy could be accommodated within any of these components.

The disease burden and its cost implications is another consideration for policies to be prioritized. Cervical cancer, they noted, is the number one cause cancer-related deaths among women and a policy to vaccinate against such a condition is within the scope of the overall health policy. Other factors that may be considered in prioritization process include gender and equity concerns for service provision as the National Health Policy applies them. As cervical cancer affects women, interventions that address it reduce deaths among women, thus meeting equity and gender concerns for service provision.

With regard to the HPV vaccine itself, respondents reported that the main considerations in prioritization of the policy would include,

- Underlying cause of cervical cancer and the role of HPV vaccine in its prevention, thus the justification of HPV vaccination
- Availability of vaccine against locally prevalent sub-types of pathogens in country (Sub-types 16, 18) that would be beneficial to indigenous populations
- Effectiveness of the vaccination were it to be given to people
- Safety or adverse effects and dangers of the vaccine as compared to the known benefits of vaccination.
- Cost implications of intervention, the cheaper the better and existing mechanisms for integrating vaccination into the health system.
- Acceptance and compliance, taking into considering people's willingness to receive the vaccine.
- Available information to enable the development of a policy that works well and is in harmony with already existing ones, not conflicting with local or international agreements.
- Timing for introduction of intervention should use opportune timing considering that MoH was currently focused on efforts to control non- communicable diseases, including cancer.
- In addition to risk factors of cancer of the cervix, and the benefits of the vaccine, members of parliament indicated that if the vaccine has the 'blessing' of the ministry of health, they would find no problem advocating for its prioritization.

Policy makers at various levels recommended studies on cost implications, and compilation and dissemination of scientific evidence on the safety and effectiveness of the HPV intervention.

7.4.4 Champions in Policy formulation and Implementation

National Level

The following were reported to be champions in terms of policy advocacy, implementation and monitoring. At the national level, the MoH works through its RH Division, which would provide the leadership by forming a Technical Working Group that would work closely with EPI and the School Health Program within the Maternal and Child Health Department. RH Division works closely with technical working groups in other Departments including Planning to draft the policy, which they present to the Technical Review Committee in the Planning and Research Directorate, then to Senior Management, Health Policy Advisory Committee (HPAC) and Top Management. Other actors include representatives of relevant line ministries such as Education and Sports, Gender and Finance. The National Health Assembly and Cabinet can also play an important role in advocacy for policy. Development partners, NGOs, medical professional bodies and faith-based organization responsible for providing services are critical partners.

District Level

At the district level, LC5 Council Members, LC3 Chairpersons, religious leaders and traditional leaders, were mentioned as key movers for implementation. The media and activists at both levels were reported to be vital, if these are properly mobilized and reached, could play a complementary role to others for success. Others mentioned were NGOs and other community based organization, especially those working with youth and health programs.

Community level

At the community level, implementing champions include local government councils (LC), religious and opinion leaders, traditional or alternative health providers (TBA, TH) and community resource persons. All these were reported to be central to social mobilization for implementation an intervention and therefore were important champions for program implementation.

7.4.5 Process of Negotiation for Implementation of HPV Vaccine Policy

Policy formulation process starts off with a situation analysis to find out whether the problem in question is a public health concern. Respondents recommended compiling and synthesizing available information on cervical cancer in the country to inform development of policy and for its advocacy.

> *"First thing is to give facts – begin by showing the problem and its magnitude and give information on what is known about the intervention to ensure all appreciate it" Commissioner MoH*

Once the problem has been defined, it was stated that the line ministry (MOH) through RH Division drafts a technical paper and consults widely within MoH and with representatives of relevant sectors (education, gender, private sector) and other stakeholders to draft the policy. The draft policy is presented to and discussed in relevant structures

within the MoH (Senior and Top Management meetings and Health Policy Advisory Committee -HPAC). This process, they suggested can take up two months. They suggested that there would be need for costing the policy, include costs into sector budget plans and consult the Ministry of Finance Economic Planning and Development (MoFEPD) for budgetary support.

At national level policy makers suggested that advocacy at the topmost leadership was essential including Cabinet and Parliament for information and budget support.

> *"The matter is not a parliamentary one, only MoH top management is needed. When HBV vaccine was being introduced, it did not require parliament. Once the technical people were convinced it was viable, Top Management discussed it and was approved then it was included in the policy. The Minister in his policy statement can communicate the intervention to the rest of the people including cabinet*" senior health planner

Many respondents suggested that deliberate plans may be necessary to involve the key people for instance the Head of State or First Lady to talk about the importance of cancer cervix and benefits of its prevention by HPV vaccination.

7.4.6 Policy Implementation Strategy

Phasing

Participants suggested that if the resources are limited, implementation of HPV vaccination could be phased, starting with a few districts. However, many respondents felt that since the intervention is of known health benefit, there was need to upscale its implementation to cover the whole country.

I would advise that you don't go national too soon as this is difficult to accomplish. Do pilot implementation in several areas and also do very good advocacy especially among the politicians. Top Manager Engender Health- Kampala

Integration within other Programs

Majority of policy makers and senior managers talked to suggested that integration of HPV vaccination within existing health programs should be suitable implementation approach. Programs such as EPI, especially TT vaccination but also within the School Health Program. Given the logistics required and nature of the HPV vaccine program, the EPI would be the best program to offer services for new vaccine. EPI has an infrastructure in good shape, including the cold chain, transport and human resource. Further more, they said, immunization campaign is a tested system, with previous record of success of how leaders could be involved, and the role of districts is all known. It was suggested that HPV vaccination should be integrated in the strategic plans of EPI program and that of School Health Program.

There were some fears related to integration approach, mainly related to already existing poor integration efforts on the ground in health system, which might pause problems, as expressed by one Commissioner.

"One of the major weaknesses has been vertical program approach at level of heath unit, where a fridge for EPI is used strictly for vaccines and not any other supplies say those of RH. So does it mean that we if we are to put HPV vaccine would it mean buying additional fridges"

However, the difficulty of sharing EPI fridges with other services was explained as deliberate efforts to minimize possible fetal mistakes when drugs (such ergometrine) are mistaken and given to children instead of vaccines.

Within EPI, many discussants felt that HPV could be pig-tailed to the TT program in schools and develop a separate strategy to reach girls out of school, probably through the Adolescent SRH program. Ideally the first three doses of full TT schedule (5 doses) would tally with those of HPV vaccine (given at 0,1,6). Furthermore, TT was going to be introduced soon to upper primary pupils, targeting all girls.

However, some senior managers expressed some fear that if the vaccine was introduced right away without adequate preparation and sensitization of people it might cause problems for the TT acceptance.

"People may refuse this vaccine, then TT will equally be affected. People may wonder why girls again" School Health Manager

Other reservations to integration of HPV vaccine in EPI were related to scare resources available for EPI. They pointed out that EPI program needs new resource and massive ones and addition of a new program without adequate support may subdue EPI implementation.

Integrating HPV into School Health Program, it was reported that it might delay HPV implementation, as the program has not started yet. However, respondents from MoES reported they were developing a strategy for implementing School Health Program and were willing to consider inclusion of HPV.

Project Approach

With regard to project approach, policy makers had different opinions on how the vaccine should be introduced. Those opposed to project approach, were very firm in some cases as indicated by a senior planner in the MoH below.

"We have now become allergic to projects- Programs that come as projects have always been taken in at different levels including districts and health facilities but they have a great effect of disorganizing the system because they come with own plans and even resources and disorient services. We are now emphasizing that all programs should be integrated in the sector budget and plan because independent. Projects distort our service delivery in spite of the fact that they come with clear objectives.

Yet others suggested it might be prudent to have focused project start-off within the MoH but fully streamline it in health service delivery at a later date when more details have been worked out.

"Using the Vitamin A experience may be good. Although it was linked to EPI it was initially implemented separately and only handed over to EPI after it took off and stabilized" Senior Health Planner

7.5 Advocacy

Advocacy was reported to be the basis of the program implementation for other stakeholders to buy into plans. Advocacy must address the seriousness of cancer cervix problem, the nature of vaccine intervention and how useful it can reduce the burden of disease and economic benefits of the intervention. To reduce possible controversy, they suggested that it was mandatory to carry out high-level advocacy; the Minister of Health should solicit for Cabinet approval to get backing from colleagues.

It was recommended that advocacy should be carried out from the national level to the districts, reaching out to the teachers, parents and girls. Policy makers at the MoH recommended that the process would require a minimum period of time 3 to 6 months and the shorter the period the more intensive the efforts and resources required. Working with districts, the MoH should put in place logistics for vaccine delivery and train health workers.

The private sector, it was mentioned, needs to be brought on board for advocacy and health services delivery. It was felt that government need them and there was need to work out the kind of support they require e.g. vaccines, skills, etc. Respondents recognized that private sector has a lot of resources that could be tapped and should go in partnership in implementation of HPV. Faith-based organizations and religious leaders were mentioned as important actors and it was suggested that these should be brought on board early. It was felt that if government can purchase vaccines and support the private sector, this would ensure quality services in this case.

Members of parliament strongly felt that they have an advocacy and mobilization to play if the vaccine introduced. However, they would first have to be convinced about it themselves.

I you give me enough information, my main role would be mobilization of the people in my constituency but I can't talk about technical issues. You the health workers must come and talk the facts when we have mobilized the population for you. Our role is just politicizing the masses and putting them together for you to talk to. Member of Parliament.

Policy Communication

Policy makers at national and district level strongly felt that compliance and acceptance of HPV vaccination requires development of a good communication strategy. Policy makers suggested that a national launch for the vaccine might help to draw attention to the intervention.

The findings suggest there is need for systematic, deliberate and uniform communication process between the Ministry of Health and the Districts especially in case of new policies. Districts recommended that communication of the policy to them should be early enough to allow necessary planning and training of the health workers prior to the introduction of the

vaccine in districts. Many districts leaders strongly recommended working with the Annual National Health Assembly, which was cited as the most appropriate avenue to kick-start the mobilization and policy advocacy in districts. However, district technical officers were concerned about the current procedure for communicating policies to the districts and to the communities, indicating the need for changes.

> *"The politicians should not be the first to break news about this policy, let them wait and come in later. Some politicians may rush to radio stations or meeting communicating the policy without clear facts and may make uninformed statements, which could endanger the program".*

For more detailed communication on policy, the MoH develops policy guidelines or standards that are disseminated to all districts, to guide implementation. District Health Officers may be invited for briefing on a new policy but more often the MoH develops policy guidelines and standards for policy implementation, which are disseminated together with the policy to districts. A policy dissemination workshop may be organized in a district as a way of launching a new policy.

Once districts receive these guidelines, they communicate with lower health units through a series of steps. Technical people including HSD and target discuss policy guidelines and identify target groups for dissemination. A focal person is often designated to intervention implementation and charged with responsibilities including coming up with work plan and budget. The DHO oversees the whole process including giving technical support. District sensitizes health workers at lower levels through workshops or meetings depending on availability of resources or circular letters may be used. Politicians, they said should be targeted through workshops.

7.6 Coordination and Management

Regarding appropriate coordination and management structures for implementation of HPV, participants at policy level were mostly in agreement that Reproductive Health Division should give technical support but HPV vaccination program should part and coordinated by EPI at the MoH level.

If a project approach is used for implementation, based on the experience of Vitamin A and HIPB programs, a project management unit (PMU) should to be set up in MoH to provide coordination. This PMU would oversee the program until it has taken off until it is streamlined into EPI, after a few years. At the national level, collaborative arrangements and roles between MoH and MoES for program coordination should be worked out and communicated to implementers.

At the District, the DHMT would be in charge and should provide technical leadership coordination of the program implementation. District leaders consider themselves as the custodians of national policies. Various structures in form of District Executive and Sectoral Committees comprised of politicians and technical working groups do exist and are vibrant in over seeing implementation of social policies and programs in education, health and other social services.

7.6.1 Planning

Rolling out HPV vaccination program was reported to start off with including intervention plans into MoH annual work plans. These, it was suggested, should be entered into the medium term expenditure framework and resources to support these plans should be identified. Following development of policy guidelines implementing responsible divisions of MoH (RH, EPI, School Health Program) should integrate HPV vaccination plans into their plans, budgets and work plans.

7.6.2 Implementation of HPV Vaccination in Districts

All districts concurred that while it is not their main responsibility to make national policies, they have the mandate to implement them.

> *"When a policy comes and is well explained to us, we implement it. We cannot refuse; we are government employees. In addition, there is a skilled work force; so we have technical capacity to implement government policies".* (KI Mbarara).

Administrative Structure and Management

In terms of administrative structures required in the districts, largely all interviewed agreed that creating new structures might complicate implementation. It was noted that the existing DHT structure in collaboration arrangements with Education Departments were sufficient to over see the implementation of a new policy on immunization. This would ensure harmony and avoid duplication of effort and staff.

> *"We need to look at areas where there is strength for example the existing structures (DHTs) are flexible and can be reconstituted into a task force for e.g. some teams already working on cholera, immunization etc. Such teams may be used. We also try to mobilize support from other structures. The only problem is logistics – but these structures can work. Supervision is also a challenge but we try to combine programs and teams to reduce costs". (*KI Mbarara).

Once a policy has been delivered to the district, some actions may be required to boost its success. In particular, district specific bylaws may be required during the implementation of vaccine program to increase success if response in a particular district if found to be poor. Bylaws are a common feature and mechanism used by the district leadership to enhance participation in other common good policies such as Universal Education and Sanitation policies. The process of enacting health ordinance is speared headed by the LC5 providing the political leadership, while the DHO provides technical support and a legal officer provides detail of the required actions and sanctions.

> *"Some of these are involved in providing immunization and other health services. They must be made to appreciate their role in this vaccine and once they do, they will start to provide to their clients"* (Commissioner MoH)

7.6.3 Raise District Awareness

The first step in introducing the policy should be raising awareness among health workers and the district political leadership of the extent and nature of the problem of cervical cancer. It was noted even health workers might not be knowledgeable enough about the magnitude of cervical and therefore may not see it as a great priority. Hence this awareness should be evidence based to justify in the first place that cervical cancer is a problem in our society before the idea of policy and prevention can progressively be introduced. The health officials noted that while the position of health workers is clear; to implement health interventions, they must also work with evidence.

Furthermore, for such a new program and policy it was argued, the district should be given ample time and should not be rushed. Adequate time was necessary in districts for planning activities, mobilizing and accessing resources and putting logistics in place for program implementation. Time was required to train and orient providers and deploy trained staff as well as equip service points. Technical and political leaders alike argued that a program may be good but if it is forced onto the people the effects may never be alleviated even if when attempts are made later.

> *"Remember you are talking about young girls and people must be convinced that this is the right intervention. We do not have to rush the policy at all. You should engage people – take evidence – films, pictures, etc and give people a chance to reflect on the development of the disease, the stages and the implications.*(KI Mbarara)

> *"We are still in the middle of the controversy caused by DDT and indoor residual spraying and the leaders are finding it difficult to implement it. It is only yesterday that council agreed to it (DDT spraying) and gave it a go ahead but some students in some schools are already striking against it".* (KI Gulu).

7.7 Monitoring of HPV Vaccination Program

At the central level, it was recommended that monitoring of the vaccination program should be integrated in existing routine monitoring systems, but program indicators need to be developed. Issues that needed to be monitored apart from coverage included how the various levels had embraced implementation of program, their support and level of integration into their budgets.

Coverage would be captured annually by HMIS but adverse effects following the immunization could be monitored periodically. Impact of program or cost-effectiveness requires longer periods and periodic national surveys such as the UDHS could be used. Changes in people's knowledge and attitude towards the intervention could be determined with periodic surveys.

Other opportunities for monitoring were during the joint planning with the districts where 4 regional teams of planners at the MoH go to districts to help in developing annual plans and these could be used to monitor HPV vaccination program. Quarterly plans reviews at MoH offer an opportunity for monitoring program and sharing information on its performance at the center. Other national level opportunities for feedback on progress made include during the National Health Assembly (brings together people from all districts) and

the Joint Review Commission with development partners. Special monitoring can be done by special program like UNICEF as part of their program and emergency monitoring.

The district political and technical leadership consider that by virtue of their offices they have a major role to influence and monitor policy implementation. Districts suggested that vaccination program should be part of their routine monitoring and supervision for health services. They mentioned a need to develop appropriated reporting format, train staff in recording and reporting essential data, cautioning about the possibility of over loading the HMIS and immunizations forms.

7.8 Sustainability

Sustainability concerns related mainly to ownership and cost of the program. Respondents at the national level emphasized that government must own the program through the MOH, for without this ownership; HPV vaccination may easily be misunderstood to be an experiment. The support of the Committee of Parliament on Social Services should be sought early as it has been found useful it the past with difficult situations.

District support for the program is critical to ensure ownership and sustainability and was viewed as critical for success of program. This would call for strong advocacy at district level for the district to appreciate HPV vaccination as a solution to a problem affecting their people to which urgent intervention was needed. However, some district leadership had cautioned against heavy donor influence that might negatively impact on ownership of the initiative.

There is noteworthy interest among policy makers and implementers in undertaking HPV vaccination as it is viewed a potentially longer-term solution to the fetal condition, cervical cancer. To introduce the vaccine, a completely new policy is not required but existing RH and EPI policies should be reviewed to address the overarching cervical cancer priorities as screening and prevention. This will accommodate vaccination against HPV as a key strategy for prevention of cancer cervix.

The findings strongly suggest that policy guidelines embodying national standards and capacities of Uganda to undertake this intervention will be needed. This would serve to inform the public at large on the need for vaccination against cervical cancer; which is less obvious and so little is known about, prioritize the intervention and mainstream it into on going programs and provide legal and regulatory framework for implementation. The national standards should be based on best practices from immunization programs such as the Child Days Plus Strategy (CDPS) and routine outreach, which could be adapted to integrate HPV vaccination. This will introduce the intervention within a realistic framework of available resources and program priorities, adapting best practices to suit the existing resources and capacities.

The process of successful development and implementation of the vaccine initiative was considered to depend heavily upon the momentum and leadership from the national level in MoH and the district commitment to the program. Critical information on the magnitude and current status of cervical cancer in the country, benefits of offering HPV vaccination to

young girls, safety of vaccine and compliance and acceptance of the vaccine requires quality advocacy.

Advocacy was highlighted to be the basis of successful implementation and comprehensive information and education strategy to reach all other stakeholders was recommended. Advocacy for this vaccine should go beyond influencing the political decision to raising awareness among all stakeholders including health workers, for duration of not less than 3-6 months). It was suggested that advocacy should focus on the cancer cervix as a problem, and how it should be addressed, damage control, and prevention of dangers misinformation, and roles for each stakeholder. Inclusive and early mobilization for effective participation and involvement of all key partners especially the MoES, Gender and the Local Government, was important.

Planners at all levels underscored the need for commitment from government, both at the centre and in districts to reflect in their budgets funds for effective logistics to support the vaccination program and training and supervision of staff. Harmonized planning, level of funding, vaccine procurement and availability of skills were critical for program success

Regarding policy and program implementation, HPV vaccination should be integrated in MoH annual work plans and the medium term expenditure framework. Both RH and EPI would develop policy guidelines, with in put from other stakeholders such as School Health Program and EPI. Integration of the vaccination program within the EPI and if possible were tied to the TT in Schools, and development of a separate strategy to reach girls out of school, probably in the Adolescent SRH program, was suggested.

Government and district ownership of the program was viewed, as corner stone for sustainability and clear roles for different stakeholders were essential for harmonized implementation. Central to the success and sustainability of the intervention was the community acceptability of the vaccination as a safe and essential health intervention. Joint planning was recommended for central and district teams to ensure success of implementation. Districts should include HPV vaccination in their district work plans. The cost effectiveness of the policy must be brought out, to convince all decision makers that the intervention has something to contribute in terms of cost versus benefit.

Level of funding for HPV will determine success of program. Availing resources and logistics, often in addition to what is available to support EPI and to districts, for implementing HPV vaccination will be a fundamental success factor. The sources of funding are critical and should be very clear in the policy. Respondents felt additional resources would be required if districts are to implement this new policy.

> *"Districts should not be expected to contribute resources like money. It is risky when districts have no additional funds to put to new interventions. There is a tendency for central programs to leave out critical aspects like mobilization of people and argue that this is the role of district -to do mobilization – If you do this, the program is finished. In addition, we need a uniform intervention across the Country and therefore you can't expect every district to find the same amount of resources to implement the activity as would be expected". KI Mbarara.*

Procurement of vaccines for HPV vaccination program would be best through EPI. It was reported that procurement of vaccines has usually been with assistance of partners such as WHO & UNICEF, a trend that should be encouraged to ensure adequate quantity and quality and that vaccines are available on time. For success of the intervention, planning ahead and ensuring that the flow of money is not a problem must minimize delays in procurement of essential supplies.

Availability of skills to deliver intervention was reported by the center and in districts to be critical for success. Planning for recruitment and orientation of staff was emphasized as an important aspect for preparing the health workers at all levels on how to assess supplies including vaccines needed, logistics for distribution, handling and administration of vaccines and recording and reporting. The monitoring mechanism must be put in place, as it will be critical for success of the program.

The leadership offered at the center was reported to be critical for the success of the initiative. The technical working group in MoH will determine the momentum and will determine to what extent PHV vaccination is appreciated as meaningful solution to prevent cancer of cervix.

Clear roles for different stakeholders will be crucial for success. HPV vaccination program will involve several stakeholders and therefore, roles of different sectors and stakeholders should be clearly stated in the policy. Participants suggested that experiences of other countries in implementing HPV should help to build faith in the activities for adoption of the policy in the country.

Community acceptance of the HPV vaccination is critical for the success of program and for its sustainability. District officers felt that acceptance can be built on the fact that immunization, as a practice has almost become part and parcel of people's way of life and that people are now aware of the benefits arising of immunization.

> *"People are fully aware of immunization and its benefits. Immunization is a household concept – the measles campaign has given evidence that immunization works – people are seeing the results". KI Mbarara*

The success of national immunization campaigns such measles and the child health days could offer a strong basis for the acceptance of cervical cancer vaccine policy, based on reduction of resulting morbidity. Respondents made reference of these; emphasizing the important role such campaign approaches played in mobilization for participation and in monitoring implementation

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> *"The logistics for these campaigns have been fairly available – vaccines, funds, etc have been provided adequately by the central government (MOH)".KI Mbarara*

Challenges and how to address them

Implementation challenges stated were directly linked to sustainability of HPV vaccination program. Many of these, respondents felt, could be addressed by wide effective consultations, advocacy and mobilization for commitment of all levels.

- Convincing the people in general that HPV vaccination works, that it is useful and safe, given the short history of using this vaccine and the scarcity of strong evidence for impact of such program. There was need to start dialogue in the media to create vaccine awareness. National policy makers stressed the need for Government to inform providers and the public at large how unwanted effects and risks will be dealt with. Some districts leaders cautioned,

  "We should avoid making Ugandans guinea pigs for new drug trials and vaccines. Remember the sad story regarding the HIV prevention trial using gel microbicide? Let the policy be clear on what government is prepared to do regarding the risks". KI Mbarara

- Program targets girls only; moreover young ones. This gender selective nature of the program will most likely be a serious issue that requires adequate explanation to counteract possible association with fertility control of girls.

  "Targeting young girls for prevention of cancer that occurs in adult women is likely to raise questions. People would rather see prevention directed to mothers". KI Soroti

Some members of parliament too, expressed fears regarding the target group for this vaccine and felt that the HPV interventions would have rather targeted older women first.

"I am very uncomfortable with this group. Why don't you start with screening and treatment? You should focus on older women who have had at least 2 children and are over 19 years. If you find they have a positive pap smear then counseling for treatment should follow. My other worry is the risk of implying that children can now engage in risky sexual behavior". Member Parliament

- Awareness of the girls themselves and how they will be made to accept and create demand for HPV vaccination services may be a real challenge. This coupled with use of injections, which is painful and for which many have lost confidence in age of HIV/AIDS. The use of disposal needles and syringes for this vaccine can help to lessen such fears.

- Involving the 10 years old will be a challenge. How will they be convinced to participate? There is need to plan very well and make good use of the media to disseminate the message that cervical cancer has a causal relationship with HPV and the role of prevention vaccine. This may require involving the 'big guns' like to First Lady to help with advocacy and sensitization.

- Challenges include minimizing misinformation at the top level with possible resistance due to the cost implication. Information needs to be packaged well for all, allowing adequate time for advocacy (3-6 months).

- Pushing the HPV agenda too fast can be counteractive because planning; integration, coordination and monitoring of the program may pose challenges. Program implementation must be well planned and harmonized with other interventions.

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- Program logistics and requirements implications pose problems in an already under resourced health sector. Concerns were on sustainability and whether government will be able to take HPV vaccination on after the initial donor support.

> *"For instance Hepatitis B and Haemophilus vaccine is finding challenge to get into our budget. The present per capita budget is $ 28 per capita but only $ 12 is available. So a lot will depend on the cost of this vaccine" Senior policy maker MoH*

- The challenge of building a sound skills base among health workers was noted, especially among the over worked EPI providers. Yet focus group discussions among parents had indicated the desire for the vaccine to be administered by technically qualified health workers. Involving districts as the biggest partners will mobilize for support for implementation and will be the basis for necessary adjustments.

8.0 INFORMATION NEEDS AND PREFERRED CHANNELS OF COMMUNICATION

8.1 Introduction

Cervical cancer vaccine is a new health intervention and there is general lack of information about cervical cancer as a health problem. The introduction of the cervical cancer vaccine will therefore require a strong educational campaign guided by a well designed communication and advocacy strategy that will not only take into account identified information gaps, fears and misconceptions that people may have with regard to vaccines and vaccination but also address how best to reach out to the various stakeholders and partners and with what kind of messages. This formative research delved into issues of health information dissemination and gaps so as to guide the design of a communication and advocacy strategy that will raise awareness about the HPV vaccine and enhance its up-take among the target population.

A key objective of the formative research was to explore the perceptions, understanding, knowledge and attitudes of the primary and secondary decision makers regarding cervical cancer as a problem and the new cervical cancer vaccine; and to establish the nature of information needed by all the stakeholders in order to guide informed decision making. The findings from the formative research were used as a basis for the development of the communication and advocacy strategy and IEC materials. were designed based on the findings from the formative research findings. as a basis for.

8.2 Current sources of information on health issues including immunization

The formative research established that there were various sources of information on health issues. The radio was mentioned by the majority of respondents as being the most important source of health information. The liberalization of mass media industry has resulted into the proliferation of FM local radio stations. There are local FM radios in all regions of the country that broadcast programs in local languages. Consequently, various health interventions including immunization have exploited this opportunity and health messages and programs are common features on most FM radio stations countrywide. Whereas the use of the radio was found to be the most popular method for health information dissemination, it has been combined with other sources as attested by several of the stakeholders

"We get it (information) from the radio, places of worship, LC leaders and from the community by word of mouth", (FGD with Nyendo parents, Masaka district).

"We use radio programs to disseminate health information; meetings and trainings are held at health sub districts with lower health units in-charges who in turn train the community mobilizers; trained community mobilizers pass on the information to the parents", (District Health Visitor, Mbarara).

"We use the radio… we have also been developing materials that we disseminate to the community like pamphlets. Then we also try to use our film shows and organizing community talks", (District Health Educator, Soroti).

"We get such information from Radio especially radio Buddu and CBS (Central Broad-casting Service. In addition, we get information from people who move in villages speaking on micro phones. Information on health issues including child care is also got through the LCs. The LCs are first called and sensitised, and then sent back to the villages to sensitise the people and mobilise them as well,"(Head-teacher of St. Theresa Primary School Bwanda, Masaka district).

"Use of mass media (radios) for talk shows, radio spots and jingles; there is door to door mobilisation by parish mobilizers and the village health teams; announcements in churches and places of gatherings; use LCs at various levels such as sub county, parish and villages; distribution of pamphlets, posters, flyers; and through schools and other civil organisation groups", (Expanded Program for Immunization Focal person, Gulu district).

Other significant sources of information about health issues reported include: health workers, science teachers, seminars / workshops, posters, billboards, film shows, TV drama and newspapers / brochures / leaflets.

"*We also get information from posters. When these are put up we get curious and try to find out what they say,* (FGD Nyendo parents, Masaka district).

"We organize meetings and seminars for different groups of people from the community; use schools through the school health program; adolescent drama groups at sub county level; use of MOH film van followed by a talk show; distribute IEC materials to the community, market places, health units, shops, private clinics and hospitals; we use radio programs and talk shows; through council sessions at the district; newspapers, particularly Orumuri, and the health magazine that appears in the Wednesdays New Vision newspaper; hold interpersonal talks at health units and sub county; and also use churches, mosques and faith based organizations" (District Health Educator, Mbarara).

*"Information is disseminated in many avenues. These include workshops and seminars for health workers, organized by non-governmental organizations. We also disseminate information through radio talk shows. We have two programs every month. We use local radios such as Radio Buddu, Top radio, and Equator radio. We also use the Behavior Change Communication (BCC) approaches through drama shows, film shows, etc. We also use School health programs such as essay competitions, if the funds allow" (*District Health Educator, Masaka).

"One of the methods for communicating health messages is interpersonal communication. Through meetings and mobilization for sensitization, we reach various people especially pregnant mothers, parents, and village health workers…even teachers we reach them when we have an activity at school. We also use media i.e. both print (posters and leaflets mainly) and electronic. These are distributed to health facilities that display them or even distribute them to some people in the communities. At times we put some health information in the news *papers but not often….this is only good for reaching the political leaders and some professionals in the district who read newspapers often. Another media which we prefer to use for health education is the radio. FM radios have come up here and have good listernership. Our office (DHE) is the spokes person of the MoH at the district so we are often on the radios carrying out health talks, at least 2 times a week and people have come to know the program"* (District Health Educator, Gulu).

However, for school children in particular, *pull outs* of '*Young and Straight Talks'* were particularly mentioned as the main sources and school health programs such as; PIASCY which was mentioned across the five districts as an important source of information about HIV and AIDS.

8.3 Popular radio stations

As previously mentioned the liberalization of the media industry has led to the establishment of many FM radio stations and these were reportedly the most popular with a wider listener ship as illustrated below

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"Radios are popular here. Here Central Broad casting Services (CBS) and Radio Buddu are very popular and can be used in mobilizing the population…There are health programs on radio Buddu on HIV by TASO, etc. I think programs on the local radio are better" (FGD, Members of the Health Committee, Masaka district).

Table 8.1 shows the FM radio stations that were reportedly most appealing.

Table 8.1: Most Popular Radio Stations

Radio Station	District
Radio Buddu	Masaka
CBS	Masaka and Kampala
Star FM	Masaka and Kampala
Top radio	Masaka and Kampala
Equator	Masaka
Vision radio	Mbarara
Radio West	Mbarara, Masaka and Kampala
Radio Simba	Kampala
Capital Radio	Kampala
Radio Sanyu	Kampala
KFM	Kampala
Radio One	Kampala
Super FM	Kampala
Radio Maria	Kampala
Akaboozi Kubiri FM	Kampala

8.4 Most Popular Health Programs on the Radio Stations

The various stakeholders were also asked which health programs were most popular on radio stations. As shown in Table 8.2 several were suggested but one important aspect about all these health programs was that they are interactive and listeners are accorded an opportunity to call in and have their concerns/questions attended to immediately.

Table 8.2 below outlines the most popular health programs on the various radio stations as established by this formative research.

Table 8.2: Most Popular Health Programs on the Radio Stations

Program	Radio stations	District
Under the Mango tree	Radio Buddu	Masaka
Dr. Grace Nambatya on health matters *Twogere Kaale* *Ekyogero* *Manya Eddagala Lyo*	CBS	Masaka and Kampala
Omushaaho waawe "Your personal doctor" *Rock Point*	Radio West	Mbarara
Capital Doctor	Capital Radio	Kampala
Asiika Obulamu	Radio Equator	Masaka
HIV/AIDS Programs (Presidential Initiative on HIV/AIDS-PIASY; Immunization, Home and personal hygiene; ANC programs		Soroti
Keeping our environment clean, PIASY	Mega FM	Gulu

8.5 Preferred sources of information on health issues

The formative research explored various stakeholders preferred sources of information with regard to health issues. Various preferred sources of information on health issues were mentioned these included: the radio, mobile film van, shows, drama / plays, schools, health facilities as well as places of worship were lauded as the most preferred sources. A number of reasons were given for the preference of these different channels. The reasons range from being convenient, easily accessible, interactive, trusted and arousing interest. However, given that communities are different, there is a need to use different kinds of channels for different people. The probability of getting information to various population groups is increased if a multi-media approach is utilized. The following are some of the observations made by the respondents illustrating their preferred sources of information on health issues.

"I prefer information from the health department because it is accurate and researched since it is their area of specialization….and school based health education talks are also good because there is a chance to ask questions directly" (Deputy Head Teacher, Mbarara district).

"I prefer Mega FM (radio)to a number of other radios…information on mega FM reaches all parts of the district….We trust it for information on health issues" (Secretary for Community Development, Gulu district LC V).

"Radio has a wide coverage compared to other media… it can reach about 1.2 million people within 30 minutes…however, radio talk shows and phone in programs are expensive" (District Health Educator, Mbarara).

"Among the different sources mentioned, I would prefer the radio because so many people more especially the mothers listen to it. It would be very good to put announcements about this new vaccine in-between the main news as announcement interludes" (Political leader, Kampala City Council)

In the FGDs with school children, they mentioned that they preferred use of drama and plays as one pupil rightly observed,

"Watching plays is like watching real life unfolding (FGD, girls St. Thereza Primary School, Bwanda, Masaka district).

While preference for the film shows is based on the fact that it attracts many people and interests them into watching, people only go away when it is over.

8.6 Best way to inform the community about cervical cancer vaccine

The research explored from the perspective of different stakeholders what would be the best way of informing communities about the HPV vaccine. Various channels were suggested to reach out to the various sections of the community with key messages about cervical cancer. The use of the radio emerged as the most feasible way to avail information to a cross-section of people.

"I think many people listen to radios. I think we should use the radio to reach the people". (Member of School Management Committee, Biina Primary School, Kampala district).

"Use the media such as; Radio West where they already have an on-going health program". (Gynecologist, Mbarara district).

For some categories of people such as children in school, teachers as well as their parents were mentioned as being the most trusted sources of information and hence remain the best channels to reach them while health facilities could target health workers and people who seek care at such centers including ante-natal mothers and caretakers of children brought for routine immunization.

"Health workers are most trusted on health issues, communities know that this is their field, and that they give us the right information. So if they are the ones to give this information on the new vaccine, then it would be accepted". (Religious leader Kampala district*).*

To reach out to policy makers and politicians on the other hand, it was suggested that national and district workshops involving all key stakeholders should be a starting point, for advocacy and mobilization for their support in this endeavor.

"Workshops are the best approach to pass on information to the district. It can be a one day or a one week workshop. The language should be simple since many people are non-medics". (Members of the district health committee, Masaka).

Another participant echoed the same view. *"I would suggest that you organize workshops for community and opinion leaders so that they can communicate whatever knowledge they have acquired to the*

rest of the masses". (Member of the school management committee, Biina Primary School, Kampala district).

Places of worship were also noted instrumental in reaching out to a cross-section of people including out-of school youth.

"Involve the religious leaders so that cervical cancer vaccine is talked about in churches and mosques. If these leaders are positive then the followers will also be positive". (Medical Officer in private practice, Soroti district).

"I would definitely prefer churches and mosques because information from these sources is trusted and would also prefer radio because of its wide coverage, meaning that those who do not get information from the churches do so get it from FM radio stations". (Religious leader, Kampala district).

There was also a suggestion of utilising political and cultural leaders such as the president, the Kabaka and the Nabagereka of Buganda for advocacy purposes. This is because these people do not only have a very big constituency but people believe in them.

"Kabaka is holding a big constituency and so are the MPs. If he stands there and educates his people, the subjects will listen. Then there are those who listen to the president". (FGD with parents at Biina, Kampala district).

Whereas the use of peers especially among children did not emerge as a best way to reach out to children one participant proposed it.

"I trust my elder sister; she is my greatest source of information". (St. Thereza Primary School, Bwanda FGD Girls pupils, Masaka district).

It was further suggested that local musicians and journalists should be brought on board to help inform the public about the cervical cancer vaccine. Efforts should be made to produce T-shirts, badges and caps etc with educational message to promote the vaccine. Organized groups such as; girl guides could also play a key role in information dissemination especially amongst their peers and should therefore be utilized in the sensitization and advocacy campaigns.

Also mentioned was the use of posters as well as billboards or burners to display information about cervical cancer and the vaccine.

"I think posters can do well. We can design some provocative posters. If all people look at them, they get the information". (Teachers FGD, St. Thereza Primary School, Bwanda, Masaka district).

Table 8.3 below summarizes the best channels to reach out to different target audiences with information about cervical cancer and its vaccine.

Table 8.3: Best channels to reach out to the community with information about cervical cancer

Information channel	School Children	Out of school children	Street children	Parents / guardians	Teachers	Local and political leaders	Health workers
Radio	X	X		X	X	X	X
Schools	X			X	X		
Health facilities	X	X	X	X	X	X	X
Posters/billboards	X	X	X	X	X	X	X
Mobile film vans	X	X	X	X			
Television (presentations and adverts)	X			X	X	X	X
Drama / songs	X	X		X			
Seminars / workshops					X	X	X
Places of worship	X	X		X	X	X	X
Newspapers / Newsletters	X			X	X	X	X
Leaflets/brochures	X	X	X	X	X	X	X
CORPS		X	X	X			
Public gatherings especially of political leaders	X			X		X	
Parents / guardians	X	X	X				

8.7 Display of posters / billboards

As previously mentioned posters and billboards were also mentioned as some of the best ways of reach out to various sections of society with messages about cervical cancer and its vaccine. However, it was emphasized that the messages displayed on the posters should speak for themselves. In order for the message displayed to reach out to a wider section of the community, use of local language was suggested as well as the need for them to be placed in strategic public places where a cross – section of people could see them.

The following are some of the proposed sites where these posters and billboards could be displayed and include: schools, health facilities, local administration offices including sub county headquarters, worship places, trading centers. It was also suggested that posters could be displayed on trees as well as on vehicles especially taxis and buses. A number of participants concurred with the proposed sites as summed up in their voices.

"Posters can be put in all public places for example in schools, at the hospital, on trees near the places of worship like Churches, and basically in places where many people gather. They can also be put at the sub-county". (Head-teacher, Masaka district).

"Political and administrative offices are particularly suggested for the display of posters because most people visit these offices". (Political leader, Kampala City Council).

"I think they should be displayed in the trading centres so that all people get to know that a vaccine has been brought". (St. Bruno Primary school, Bwanda, FGD with girls, Masaka district).

*"The schools, health centers, sub-county headquarters, trading centers, markets, drinking joints would be appropriate for display of information". (*Secretary for health and education, Soroti LC5 district).

*"I would recommend health units, churches, LC1 offices, and trading centers". (*Deputy head-teacher, Mbarara district).

"We have our open public grounds e.g. Kaunda ground or Peace Stadium; these can be used for displaying information". (District Khadhi, Northern Uganda).

8.8 Information gaps on cervical cancer

Whereas majority of people interviewed in this formative research were positive about the cervical cancer vaccine, as previously stated they raised a number of issues/concerns about cervical cancer and the proposed vaccine. It is prudent that before the introduction of the vaccine, a strong educational / a sensitization campaign is undertaken to clearly clarify these issues. This will not only motivate the girls of the proposed age group to accept the vaccine but will also get the various stakeholders including parents and guardians on board to support the intervention. These were some of the key concerns held by the people covered by this formative research. They range from what cervical cancer is to safety and effectiveness of the proposed vaccine.

"Like any other vaccine, it's a good idea. However, it is a recent discovery which has not been tried enough. We cannot be sure, it won't cause bad side effects later", wondered a medical officer / gynecologist, Masaka district.

"Give us information about this cancer disease, how to prevent it, the benefits of the immunization / vaccination". (Head-teacher, St. Thereza Primary School, Bwanda, Masaka district).

"I would need to be assured that the vaccine is effective and has no negative side effects", (Political leader, Kampala City Council).

"Another thing which I can say is that since cervical cancer has become wide spread; they should start publishing magazines …… Give a wide view on causes, what ways of preventing it, side effects and things of that nature so that people can read and spread the gospel to other members of the public". (Teachers, FGD at St Bruno Primary school, Ssaza, Masaka district).

Box 1

Questions about cervical cancer
What is cervical cancer?
What causes it?
What about a Family planning pill causing cervical cancer?
What are its symptoms?
How can it be prevented?
Which groups of women are vulnerable to cervical cancer?
How long does it take to develop when one is infected?
What is the percentage of people who are suffering from cervical cancer?
What is the difference between cancer and syphilis?
What are dangers of cervical cancer?

Box 2

Questions about the proposed cervical cancer vaccine
How safe is the vaccine?
How is that vaccine manufactured?
What are the ingredients of the vaccine?
How effective is the vaccine?
What are its side effects?
What benefits does the vaccine offer?
Can those with HIV/AIDS also be vaccinated?
Why vaccinate 10-12 years only? Why haven't you thought of 18-49 years? What about our daughters in secondary school?
Why vaccinate only girls?
Won't vaccination of girls encourage them to indulge in sex at young stage?
Can't the vaccine cause one not to conceive?
Which country has this vaccine program been successful?
Where has the vaccine been pre-tested and proved that it is effective and safe?
What are the risks / dangers if girls are not immunized?

8.9 Reaching men with information about cervical cancer

The formative research found that men were categorized among the hard to reach with health messages yet men yield a lot of powers in nearly every sphere of life including decisions of any household member to seek health care as rightly observed by the Northern Uganda District Khadhi,

"Men are the overall authority culturally so sensitizing them with information is vital".

With this realization, this formative research delved into the best ways to reach them with information about cervical cancer vaccine in order to solicit their support. One strategy, mentioned was the use of mobile van to show a film on cervical cancer because this would not only be very entertaining but would also arouse interest as well.

"Use mobile vans, and show them films for example in the trading centre. The men really like these films and can really take interest in them and the best time to show these films is in the evenings and in the trading

*centres. These films should be showing all about the disease, it's signs and symptoms and how the vaccine can prevent it". (*Deputy head -teacher, St. Bruno Primary School, Ssaza, Masaka district).

There was also a suggestion that like other sections of the society, men can also be reached with information about cervical cancer through the church.

"Men can be best reached fast through the church itself. "Rwot kweri" members are mostly men as a production group. If you go through these people you can easily reach them through their gatherings". (Health Education Officer, Diocese of Northern Uganda).

Other key strategies to reach out to men include: use of the radio, posters / billboards and targeted community sensitization meetings. There was also a suggestion that some men could be specifically trained on cervical cancer and the vaccine because they can be '*good change agents'* amongst their own peers.

8.10 Challenges

A number of challenges were identified that could hamper the advocacy and information dissemination / sensitization of the people about cervical cancer and its vaccine. In the first place, the proposed vaccine is new and may raise many suspicions as already highlighted above. Some parents and guardians may think that when they immunize their girls, they may never produce children. Such parents and guardians with such misconceptions influence others into such thinking thereby fail the intervention.

In addition, politicians especially those in opposition may pick on this vaccine and spread negative campaign so as to fail it because it's a government program. Consequently, such politicians and their followers could deliberately refuse to participate in the immunization campaigns even when they fully understand the importance of the vaccine in preventing cervical cancer.

Not to forget is the media industry if not properly sensitized; it may work against this intervention. Some media houses were reported concentrating too much on the negative messages especially on new interventions than educating people and yet they are key partners. They allow controversial debates and articles about these interventions and these may influence the public to be reluctant to accept the new health intervention.

Last but not least, if there is no good communication by the health sector, this activity will be misconceived and misunderstood. This is especially so if health workers themselves who are the custodians of health have unanswered questions about the vaccine as rightly observed by the District Health Educator, Masaka,

"It is very dangerous if health workers have not understood or don't support a program. For instance, people are rejecting Fansidar and chloroquine because health workers passed on the information that these drugs are not effective. Retracting the misinformation that is already in the community is difficult". (KI, District Health Educator, Masaka)

The results of this formative research suggest a need for sensitization of all stakeholders at all levels. This will require a strong continuous campaign targeting all sections of society including health workers. The campaigns should tackle issues that make the population appreciate the problem of cervical cancer and the need for their girl children to receive the vaccine. A multi- media approach is particularly recommended. In as much as possible efforts should be made to keep politics out of this campaign. All the leaders at various levels will need to be mobilized because they play a major role in mobilization and their constituents believe in them and so are the cultural and religious leaders. The orientation of the mass media will also be pre-requisite to solicit their continued support in the campaign.

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APPENDIX 1

Respondent Groups/Records Reviewed	Evidence for Burden of Disease	Observed health sector response/Recommendations
Midwives(public institutions) Doctors(private practice) Gynaecologists Outpatient registers(GOP, OPD) Inpatient register Theatre register	Patients seen have advanced disease Knowledge gaps regarding risk factors, detection/diagnosis of cervical cancer. Some misconceptions and wrong ideas Minimal involvement in preventive activities(paps, UVI, VIA) No mention of modern treatment methods for early stage cervical cancer(LEEP/Cryo) Low index of suspicion for cervical cancer Knowledge gaps regarding cervical cancer risks, protocols for cervical cancer management Minimal involvement in preventive activities ? skills availability for cervical cancer prevention, detection and treatment Limited knowledge regarding HPV and cervical cancer and primary prevention through HPV vaccine No provision in HMIS to capture cervical cancer data, high prevalence STIs Incomplete patient information, no referrals in/ out in most units. High bed occupancy by patients with cervical cancer. Deaths from cervical cancer not routinely recorded Disease stage not routinely recorded after EUA. Lost information from EUA's performed on ward. Data not synchronized with inpatient register to update final diagnosis. Heavy workload presented by EUA's	Develop national screening guidelines/policies, train and distribute to health workers Develop treatment protocols, posters, brochures on cervical cancer. Review training curricula and emphasize skills training (preventive activities) Establish libraries with audiovisual aids Need CME sessions on cervical cancer Improve support supervision by higher cadres and provide on job skills training Revise HMIS to capture cervical cancer data. Standardize cervical cancer data collection and train health workers in this Scale up preventive services and emphasize primary prevention including cervical cancer vaccine Establish regional centers for palliative radiotherapy Need for further research into cervical cancer in our setting(disease presentation/progression. KAP concerning cervical cancer in different populations etc)

BURDEN OF CERVICAL CANCER IN 5 DISTRICTS OF UGANDA

	Kampala District	**Gulu District**		**Soroti District**	**Masaka District**		**Mbarara District**	
parameter	Mulago Hosp	Gulu Hospital	Lacor Hospital	Soroti Hosp	Kitovu Hospital	Masaka Hospital	Mbarara	Mayanja Memorial Hosp
1. Suspect Cacx cases in GOPD in past 1yr	484	1042 total gyne cases. 12 cases of cervical cancer	NR	2.4% of total hospital OPD. 18 patients of Cacx out of 1040 gyne outpatients seen on gyne ward	Kitovu uses HMIS and Cacx is missed.	29 but 27 confirmed by pathology	2 per week	2-3 per week
2. Cacx cases admitted to gyne ward in past 1 yr	430	No data	NR	2111 gyne cases of which 51 had Cacx	No record	Records in the wards were not accessible	21	3
3. Proportion of gyne beds occupied by Cacx	82/129	No data	NR	No data	Kitovu hospital had no specific Cacx data	5%? Verbal report/estimate by Masaka hospital gynecologist.	3/15 [20%]	NR
4. Average duration of hosp stay (admission to diagnosis)	10weeks	3-4weeks	NR	6-16days	No record	7days	2 days	1 day
5. Referrals out	0	No data	NR	2	No record	Masaka Hospital: 5 diagnosed with advanced disease and referred for RT ??	No data	NR
6. Referrals in	No data	No data	NR	Self referrals mostly. No record of referrals from lower health units	No record	Masaka Hospital: 50 referred from lower health units	No data	NR
7. Cacx deaths (as a proportion of gyne deaths)	26/37	No data	NR	2 cases out of 8 gyne deaths in 1 yr [25%].	No record	1 of the 5 cases with advanced disease died [20%]??	No data	NR
8. Preventive services	UAVI,VIA,Pap Smear,	None, only 2 specs	NR	UAVI,VIA,Pap Smear,	None	UAVI, VIA	UAVI, Pap smear	No service yet
9. Reasons for not having services	No HPV facilities	No facilities	NR	Lack of funding and expertise	No plans yet at Kitovu	Lack of funds. Pathologist visits Masaka hospital.	No data	
10. Treatment facilities	Cryo, LEEP, Surgery, RT	Surgery	NR	Surgery	Surgery	Surgery, LEEP is faulty	Surgery	124
11. Total Gyne surgery cases	494	146	No Record	217	NR	30	No data	2
12.	195	No data	No data	7. Some done	NR	29	No data	0

	Kampala District	Gulu District		Soroti District	Masaka District		Mbarara District	
EUA's				on ward, not recorded.				
13. Number of Surgeries for Cacx	1 Wertheim's	18	10% of surgeries were for Cacx	12	NR	1 Wertheim's	No data	0
14. Frequency of cervical cancer cases by stage at diagnosis	I : 4 II: 25 III: 66 IV: 8	No data	No data	No data	NR	No data available	No data	NR
15. Distribution of Cacx cases by age	21-30 yrs: 4% 31-40 yrs: 20% 41-50 yrs: 40% 51-60 yrs: 20% 61-70 yrs: 8% Above 70 yrs	Not collected	Not collected	Not collected	Not collected	Not collected	Not collected	Not collected
Distribution of Cacx cases by region/district	Only villages recorded	Not collected	Not collected	Not collected	Not collected	Not collected	Not collected	Not collected