

Draft Report

**REASONS FOR THE DELAY IN DIAGNOSIS OF
COMMON CANCERS (BREAST AND CERVIX)
AMONG WOMEN IN TAMIL NADU:
A MIXED-METHOD STUDY**

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List of Abbreviations

WHO – World Health Organisation

GLOBOCON – Global Cancer Observatory: CANCER TODAY

HBCR – Hospital Based Cancer Registry

TNM – Tumor, Nodes, Metastasis

FIGO – The International Federation of Gynaecology and Obstetrics

FGD – Focus Group Discussion

IDI – In-depth Interview

OPD – Out Patient Department

HCF – Health care facility

HCP – Healthcare provider

HPV – Human Papilloma Virus

KMC – Kilpauk Medical College

IOG – Institute of Obstetrics and Gynaecology

PO – Project Officer

PI – Principal Investigator

HBCR – Hospital Based Cancer Registry

NCD – Non-Communicable Diseases

ANM – Auxiliary nurse midwife

VHN – Village Health Nurse

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EXECUTIVE SUMMARY

Purpose of Study

In India, the incidence and mortality rate of both breast and cervix cancer continues to remain high, as more than half the cases are diagnosed at later stages - locally advanced or metastatic stages. Studies have established that the delay in the early diagnosis of cancer, compromises the treatment, prognosis, survival rates, and quality of life of patients. The delay might be due to various reasons namely presentation delay - time lag between the recognition of symptoms to first healthcare provider consultation or treatment delay - first provider consultation to initiation of treatment. This study was thus aimed to assess and explore the factors and reasons behind the delay in diagnosis of breast cancer and cancer cervix among women from the perspectives of patients and health care. The study also explored the barriers for the delay and reach of cancer screening among the target population, that is, women in the reproductive age group of 18 – 49 years.

Evaluation methods

Sequential Explanatory study design has been employed where the quantitative component (Descriptive study including breast and cervix cancer patients) was explored first followed by the qualitative component (Grounded Theory Approach). The study was conducted between October 2021 – December 2021 in the oncology department of four tertiary healthcare facilities, where breast and cervix cancer patients who attended OPD were enrolled for the study. Patients who attended Gynaecology OPD for other non-cancerous ailments were recruited as non-cancer participants for the study. The socio-demographic and behavioural characteristics including assessment on their knowledge, attitude and practice towards cancer screening was used for the quantitative part of the assessment followed by a structured open-ended interview guide for qualitative approach (FGD and IDI). In-depth interview of the key informants, in the health care was conducted among stakeholders in various positions in healthcare. The analysis and evaluation of study findings were completed by March 2022.

Key Findings

The socio-demographic characteristics of patients suggesting that 40 – 60 years of age, low educational qualification, multiparous women, lower-middle-income community, family history of cancer, inadequate importance to health, and no previous history of cancer screening

are at higher risk of acquiring cancer of both breast and cervix and also a potential risk factor for delaying the diagnosis of cancer.

Regarding the delay in diagnosis, an average (mean) time interval of 9 months was found to be the average time duration between noticing their first symptom and confirming cancer diagnosis in both breast and cervix cancer cases. The predominant factor for the delay was the patient themselves and the commonest reasons behind them were

- Lack of knowledge or awareness about signs and symptoms of the disease
- Laxity or lethargy among daily wage workers
- Incomprehension about the seriousness of the disease
- Poor care and support from family
- Lack of knowledge about whom to approach
- Poor monetary support

Also, the significant time interval (between noticing first symptom and diagnosis of cancer) that increased the risk of advancing stage of disease in breast cancer was 2 months and in cervix cancer was 5 months. This indicated that the patients' appraisal of symptoms was delayed and any time duration beyond that posed the risk of advancement in their stage of disease

The commonest reasons behind healthcare delay were

- Missed Opportunity to diagnose
- Misinterpretation and inappropriate treatment by HCP
- Delayed handling of diagnostic reports
- Poor communication between patient and provider

The barriers for cancer screening and early diagnosis reported in our study were

- Lack of knowledge or awareness about the disease
- Incomprehension of people regarding the clinical picture of cancer (both breast and cervix)
- Misconceptions, fear and social stigma regarding regular check-ups and screening, especially in rural areas.
- Inadequate number of cancer screening camps and manpower in screening camps
- Inadequate knowledge among people regarding which healthcare provider to approach.

The facilitators that would enhance the existing system of approach and early diagnosis of cancer cases concluded from our study were –

- Promoting self-examination through female health workers for breast cancer,
- Opportunistic screening at health facilities,
- More screening camps in the workplace and periodically conducted by management.
- Patient-friendly gender-sensitive screening,
- Enhanced role of women support groups where they can openly discuss such sensitive issues

Overall, the factors and reasons behind the delay in diagnosis were inadequate knowledge about the disease and lack of self-care and family support. The need to strengthen primary health care sector in cancer detection and treatment is being a key finding of the study.

Recommendations

The following suggestions by patients and stakeholders (healthcare) are being presented as key recommendations –

- The importance of regular screening for breast and cervix cancer and its impact on early detection can be educated through promotional videos where two comparing corresponding scenarios of women undergoing early and late detection of cancer and their experience and journey through the process of treatment and post-treatment quality of life.
- Awareness regarding the importance of screening in the early detection of breast and cervix cancer can be promoted among college-going under graduation students. This is because the mothers of these young adult population will be in the potential age group at risk of getting breast/cervix cancer and thus the targeted age group for health promotion. They can be educated on the need to undergo screening and can be encouraged to take their mothers for screening tests.
- State-wide screening camps can be conducted all through the year for both breast and cervix in every part of the state, instead of just one month a year (example – October for Breast cancer awareness). All through the year, the promotion of cancer screening will ensure no woman in targeted age group is left out or left unscreened and this will also relieve the time constraint for working women.

- Exclusive centre for cancer screening can be established inside the premises of all tertiary care hospitals in order to identify potential cancer suspects and ensure immediate follow-up on diagnosis and treatment care.
- Exclusive female healthcare personnel (eg. Healthcare nurses) can be appointed at screening camps to sensitise people on the importance of screening and early detection and coordinate potential suspect cases for regular follow-up to nearest referral centres by tracking using their contact details.
- Adequate training for general practitioners and nurses at primary referrals on cancer screening and early clinical presentation of breast and cervix cancer can be given to avoid any misdiagnosis and ensure early detection.
- Active engagement of VHNs to facilitate in raising awareness, identifying suspects and promoting effective referrals during door-to-door visits.
- Grass root collaboration with Community-based NGOs to educate and motivate general people on the importance of breast self-examination and cancer screening (specific to breast and cervix) and regular surveillance on whether women above 30 years of age had undergone screening tests.
- Effective promotion of HPV vaccines, their purpose and impact on cervix cancer prevention and their availability in which healthcare centers can be done, especially in higher secondary schools.

6) Study Background

6.1. Global Cancer situation

According to the estimates from World Health Organisation (WHO), cancer was the second leading cause of death worldwide and the overall burden has been increasing rapidly in past decades, especially in developing countries. The estimate of the global burden of cancer-based on GLOBOCAN 2020 showed approximately 19 million new cases and 10 million deaths were due to cancer. For both sexes combined, one-half of all cases and 58.3% of cancer deaths were estimated to occur in Asia in 2020 followed by Europe accounting for 22.8% of global burden and 19.6% of deaths due to cancer.

Among the top 10 cancers, female breast cancer was the most commonly diagnosed cancer (11.7% of total cases), closely followed by lung (11.4%), colorectal (10.0%), prostate (7.3%), and stomach (5.6%) cancers. Lung cancer was the leading cause of cancer death (18.0% of the

total cancer deaths), followed by colorectal (9.4%), liver (8.3%), stomach (7.7%), and female breast (6.9%) cancers. The most commonly diagnosed cancer in women was dominated by 2 cancer sites: breast cancer (159 countries) and cervical cancer (23 of 26 remaining countries). The mortality profile in women was more heterogeneous, with breast and cervical cancer as the leading causes of cancer death in 110 and 36 countries, respectively, followed by lung cancer in 25 countries (1).

6.2. Common cancers among women in India

Globally, India ranked third in reporting cases of cancer, with approximately 1 million cases and half a million deaths every year. Of overall cancer cases, 70% of patients were women and the most common forms found in India were Breast, Cervical and Oral cancer (2). Epidemiological studies showed that 70 - 90% of all cancers were environmental and lifestyle-related factors were the most important causative factor behind them, which was preventable (3).

Among common cancers affecting women, Cancer of the breast and cervix were the most common. The highest burden of breast cancer was observed in metropolitan cities than rural and suburban areas. Over the past few years, there had been a steady increase in the trend of incidence of breast cancer, whereas cervix cancer was on the decline (4). This decline was attributed to be either due to improvement in general lifestyle among women or a miscalculation

6.2.1. Breast Cancer

Breast cancer was emerging as the leading cancer which affected more than 1 lakh women in India in a year. One in 28 women were likely to develop breast cancer in their lifetime and this was higher in urban (1 in 22) than in rural (1 in 60) (5). It was also more common in the younger age group where almost 50% of all cases were in the age group of 25-50 and more than 70% of the cases presented in the advanced stage had poor survival and high mortality.

A large number of factors were identified as risk factors for the disease like late age at first pregnancy (greater than 30 years), single child, a high-fat diet, and late age at menopause were some of them. Physical activity was found to be protective against breast cancer. Dramatic changes towards affluent life style and sociocultural environments had reduced physical activities to a minimum and increased the consumption of diets rich in fat. High-fat diets during the pubertal age and obesity in the post-menopausal age were risk factors for breast cancer (3).

6.2.2. Cervix Cancer

The second most common type of cancer in India affecting women was known to be caused by the growth of abnormal cells in the cervix which was the lower part of the uterus that opens into the vagina. In many cases, a complete cure is possible, but this possibility was reported to be present only if the disease was diagnosed at an early stage. The main symptom was any form of abnormal vaginal bleeding such as bleeding after sex, after menopause, or after the menstrual cycle is over. Pain in the lower abdomen and pain during sex were other common symptoms. Diagnosis was done by taking a Pap smear which was a small sample of cells from the cervix to see if there are any abnormal cell growths. A tissue biopsy was also usually done. Depending on the results, other tests were known to be advised to reach a firm diagnosis (2).

There was a marked difference in the distribution of cancer sites across different regions of the world. In contrast to developed countries, cervix cancer was a public health problem in developing countries like India, so much so, that the country alone accounted for one-quarter of the worldwide burden of cervix cancers. It was one of the leading causes of cancer mortality, which accounted for 17% of all cancer deaths among women aged between 30 and 69 years. It was estimated that cervix cancer contributed to approximately 6 – 29% of all cancers among women and approximately 1 in 53 Indian women suffered from cervix cancer during their lifetime while it was 1 in 100 women in more developed regions of the world (6).

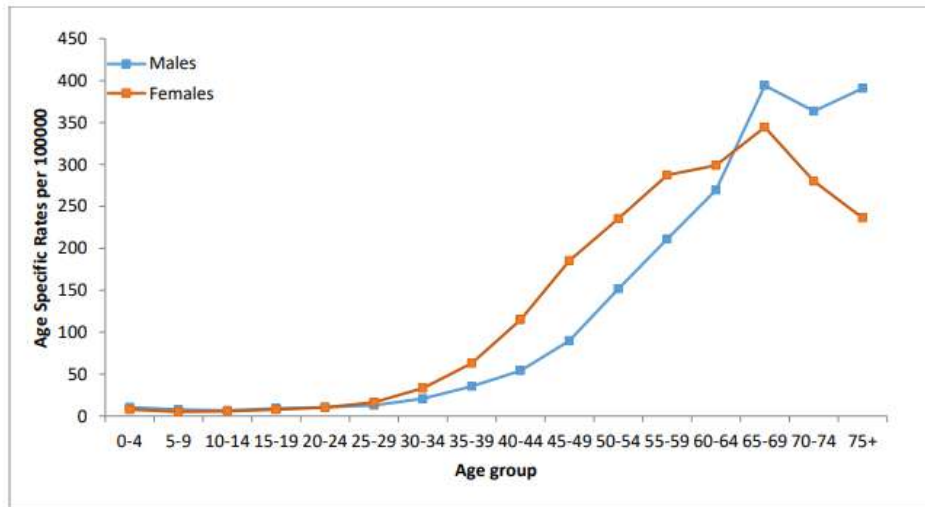
However, there has been reported a decline in trend of incidence of cervix cancer cases in India which may be attributed to be due to improvement in living standards of women in the country or may be an underestimate due to underdiagnoses, especially in rural areas (4).

In developed countries, cervix and breast cancer incidence and mortality had decreased by more than half over the past 30 years after the introduction of formalized screening programs. However, in India, the average percentage of women undergoing cancer screening was still less than 10%. This indicated the reason behind the increasing incidence of cancer in the country in past decades and the need for an increase in awareness about the disease and its screening procedures among women.

6.3. Cancer prevalence in Tamil Nadu

The projected annual incidence of all cancer cases in the state was 78,641 (2020) of which 56% are females and the cumulative risk of getting cancer of any site in their lifetime was 1 in 11 in females (7).

Figure 1: Age-Specific Incidence Rates (All sites of Cancer - 2016) (8)



Breast cancer was the leading site of cancer among women accounting for 26.3% of cases followed by cervix cancer accounting for 20.6% of cases. The overall incidence rate of occurrence of cancer in the state was 84.2 per 100,000 population which was higher among women (93.9) than men and it was also reported to be higher in urban areas than in rural and suburban centers (9). The average percentage of women who had undergone breast or cervical cancer screening was less than 10% in both urban and rural indicating the need to improve awareness about the disease and the need for screening among women (10).

6.4. Factors associated with common cancers among women

Numerous factors were known to be associated with common cancers among women, especially breast and cervix and it was essential to understand the risk factors for prevention. The commonest risk factor was higher age above 50 years followed by tobacco or alcohol consumption. Family history of cancer was a known risk factor for inducing genetic mutations and obese women or women with poor physical activity were at higher risk (11). Having the first pregnancy after age 30, not breastfeeding, and never having a full-term pregnancy were reported to be other risk factors for breast cancer while having given birth to 3 or more children or having multiple sexual partners was a high risk for cervix cancer (12).

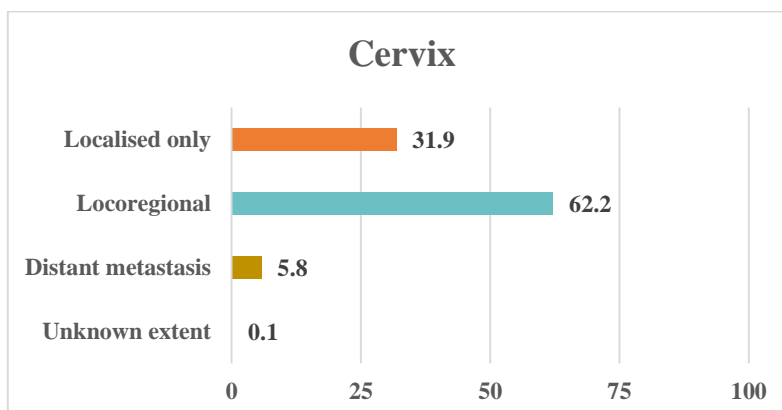
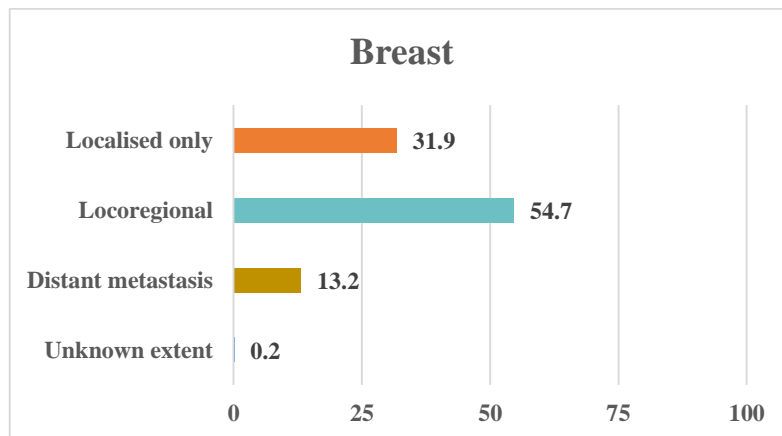
With numerous factors known to pose the risk of developing breast or cervix cancer, they were often overlooked or ignored which resulted in diseases that were often diagnosed during late stages of illness among patients. This was attributed to be due to various reasons and this study thus aimed to explore the commonest factors behind this delay in diagnosis among women with breast and cervix cancers in the state.

7) Rationale

In India, Gynaecological cancers, including breast cancer, accounted for over half of all cancers in women. Approximately 1.5 lakh women were reported to have been diagnosed with gynaecological cancers. Among them, nearly half of the cases were breast cancer (49.88%) followed by cervical cancer (29.8%) (HBCR 2021). Cancers of breast, cervix and ovary were recorded in higher proportion in the younger age group of 45-49 years than other gynaecological cancers. Especially, from the young adult age group above 25 years, Breast cancer was the major cancer type in all age groups (8). Women in the age group of 30 – 40 years reported more breast cancer cases and those in the age group of 60 – 70 years reported more cervix cancer cases in the country.

Concerning histopathology, epithelial tumors (infiltrating duct carcinoma – 89.7%) were the most common histology of breast cancer, and squamous cell carcinoma (60.1 %) was the most common histology of cancer of cervix. The clinical extent of disease for breast and cervix cancers are mostly loco regional (50 – 60%) followed by the localized site of affection only (30%).

Clinical extent of disease (%) for all breast and cervix cancer (Source: HBCR 2021) (8)



This indicates that more cases were identified and reported in their second and third stages of illness (loco regional), especially after nodal involvement. The stage of diagnosis of cancer is highly relevant to establish the prognosis of the treatment and quality of life of patients affected. Various studies have reported that the later stage of diagnosis compromises the treatment prognosis and survival rates of patients as the survival rate was found to reduce with increasing stage of disease diagnosis. Also, involvement of either node/site had poorer survival rates than those with no involvement. The survival rate of cancer patients was also found to have correlations with their socio-demographic characteristics namely age, educational qualification and place of residence.

The survival rates of patients with breast cancer in stages I, II, III, and IV were 83.5%, 80.6%, 66%, and 37.1% respectively. Whereas the survival rate of patients with cervix cancer diagnosed in stages I, II-III and IV were 92%, 58%, and 18% respectively. This shows that in both cases, cancer-affected women when diagnosed with localized or distant metastasis uncompromisingly lose 20 – 50% of chances of survival in comparison to those diagnosed in the earlier stage of disease (13) (14). Also, the 5-year survival rate of breast cancer patients was 76.0% for those aged below 50 years, 74.4% for literates or people with higher educational background, 73.3% for non-urban residents, and 72.5% for those with squamous cell carcinoma histology.

The diagnostic delay is being reported to be due to various reasons and factors involving both the patient and healthcare sector. Reporting at later stages of disease had thus contributed to increased mortality rate (both breast and cervix) in the country and this delay has also been established to compromise the treatment prognosis, survival rates, and quality of life of patients. The delay might be due to various reasons namely presentation delay - recognition of symptoms to first provider consultation or treatment delay - first provider consultation to initiation of treatment.

Mean duration and factors associated with delay in diagnosis

A mixed-method study North-East India by *Kumar et al. 2019* estimated the overall delay in diagnosis and treatment in breast cancer and the associated factors, and the median duration of delay was 203 days. The delay was categorized into presentation delay and treatment delay, where the average duration of presentation delay was 35 days while that of treatment delay was 130 days (15). This was similar to a multinational analysis conducted among 6588 breast cancer patients from 12 countries by *Jassem et al. 2014* which showed the average time duration of

delay due to system-related delay (treatment) was higher than that due to patient factors (presentation). The average duration of patient-related delay was 4.7 weeks while that of system-related delay was 11.1 weeks. The overall time delay (of both) was 14.4 weeks (16).

Commonest reasons for the delay

The reasons for delay from patients' and providers' perspectives were explored in various studies along with the pathway of care which showed various similar reasons. The commonest reasons observed from the mixed-method study by *Kumar et al. 2019*, for the presentation delay were misconception about the disease, perceived stigma, fear and denial of cancer, attribution of symptoms to trivial conditions, higher education, family responsibilities, and embarrassment of breast examination by a male doctor. Treatment delay was due to initial visit to, misclassification of disease severity, dissatisfaction with care at public facilities, poor accessibility and affordability, fear of treatment and its side effects (15).

In addition to these, there were few other reasons for behavioral delay identified in a retrospective cohort study conducted by *Heath et al. 2019* among breast cancer affected women above 40 years of age at the time of diagnosis to assess for factors contributing to the total delay in care, and specifically the behavioral delay-interval portion of that delay. They were health system utilization factors contributing to the behavioral delay, including dependents/pressing matters, employment responsibilities, transportation costs and difficulty, fear of being judged by healthcare workers, and fear of not being able to afford treatment (19).

Various qualitative studies conducted over the years to explore the factors and reasons behind the delay in diagnosis revealed certain other patient and healthcare system-related issues.

An exploratory qualitative study conducted by *Benemariya et al. 2018* among women with cervical cancer to explore the perceived factors contributing to their delayed consultation showed lack of knowledge, cultural practices, age-related factors, fear of people knowing, and socioeconomic factors to be the commonest. This was similar to another qualitative study conducted by *Tesfaw et al. 2020* among breast cancer affected women in North west Ethiopia, which showed a lack of knowledge and awareness about breast cancer, cultural and religious beliefs, economic hardships, lack of health care and transportation access, fear of surgical procedures and lack of trusts on medical care to be the major reasons for late presentation (21).

Barriers and facilitators for early diagnosis

The barriers affecting a women's decision-making process in cancer detection, presentation, and treatment collected from various studies revealed certain factors like lack of health literacy, low accessibility of the program (in respect to cost and distance), and disrespectful treatment by healthcare workers (25).

The views of cervical cancer patients on their symptom appraisal and interpretations, and their help-seeking including lay consultations when explored in various studies like the one conducted by *Mwaka et al. 2015*, showed that patients often misattributed their gynecological symptoms, and experienced long appraisal and help-seeking intervals. Prompt help-seeking was frequently triggered by perceived life-threatening symptoms such as heavy vaginal bleeding or lower abdominal pain; symptom burden sufficient to interfere with patients' work routines; and persistence of symptoms despite home-based treatments (29).

Deficits in cervix and breast self-awareness and knowledge of cancer symptoms delayed women's interpretation of bodily changes as being abnormal. All women were found to have first noticed breast lumps or gynecological symptoms, however, many did not perceive it as abnormal until additional symptoms were present. Good attitude towards health, attribution of symptoms to aging, and past benign breast or cervix disease were found to result in women being complacent about bodily changes. Disclosure to family members served as a trigger to seek healthcare. Also, the initial type of primary level care services women accessed was influenced by perceptions of care each service provided, finances, structural factors, and personal safety related to the physical location of services (18).

This study was thus undertaken to assess and explore the factors and reasons behind the delay in diagnosis of cancer of the breast and cervix among women. The study also explored the barriers to the delay and reach of cancer screening among the target population, that is, women in the reproductive age group of 18 – 49 years. This would help us to understand the beliefs, attitudes, and health-seeking behavior of women and develop public health policies and strategies that would ensure nation-wide reach of cancer screening programs and early detection of cancers affecting women, as it is of paramount importance to ensure reduction in mortality rates and increased quality of life.

8) Objectives

General

To explore the factors for the delay in diagnosis among women with breast and cervix cancers.

Specific

- To understand the beliefs, attitudes, and health-seeking behavior of cancer-affected women and their families.
- To identify the barriers of delay resulting in the late diagnosis.
- To understand the facilitators for the early diagnosis.
- To assess the reach of cancer screening among target population: women of reproductive age group 18-49 years.
- To address the family and social support for the women afflicted with Breast Cancer and Cancer Cervix.

9) Methodology

9.1. Research design

Sequential Explanatory study design has been employed where the quantitative component (Descriptive study including breast and cervix cancer patients) was explored first followed by the qualitative component (Grounded Theory Approach).

9.2. Study sites

- 1) Government Royapettah Hospital, Chennai.
- 2) Kilpauk Medical College, Chennai.
- 3) Cancer Institute (WIA), Adyar, Chennai.
- 4) Institute of Obstetrics and Gynaecology, Chennai.
- 5) Rajiv Gandhi Government General Hospital, Chennai

9.3. Study sample, participant recruitment and consent procedures

Breast and Cervix cancer patients of all stages attending Oncology OPD and non-cancer patients attending Obstetrics and Gynaecology OPD for other ailments.

The participants were recruited to various groups based on the recruitment (group) criteria and informed consent obtained before the commencement of the study.

9.4. Study period

8 months (October 2021 – May 2022)

9.5. Sampling Method

A *Maximum variation sampling* method was used where both breast and cervix cancer affected patients (all stages), non-cancer participants and various stakeholders including NCD Programme officers, Oncologists, Staff nurses and Patient Counsellor were interviewed.

9.6. Sample Size

13 Focus group discussions (FGD) were conducted where each group constituted 8 participants in the following pattern –

FGD group 1: Stage I Breast cancer affected patients (2 groups)

FGD group 2: Stage II – III Breast cancer affected patients (2 groups)

FGD group 3: Stage IV Breast cancer affected patients (2 groups)

FGD group 4: Stage I Cervix cancer affected patients (2 groups)

FGD group 5: Stage II – III Cervix cancer affected patients (2 groups)

FGD group 6: Stage IV Cervix cancer affected patients (1 group)

FGD group 7: Non-cancer participants (2 groups)

A total of 89 cancer – affected patients and 16 non – cancer participants participated in FGD which was followed by In-depth interviews (IDI), where 2 participants from each group were selected and interviewed. Interviews and discussions were conducted till the maximum saturation point of information were achieved.

Regarding non-cancer participants, 100 patients who attended Gynaecology OPD for other non-cancerous ailments during our study period were included for the quantitative descriptive study and among them, 16 participated in the FGD and IDI.

9.7. Operational Definition

Breast Cancer patients – Patients who were tested and diagnosed with Breast cancer attending Oncology OPD in our respective study settings were enrolled for the study. Their stages were registered by the OPD as per the TNM staging: Stage 0 to 4 as per AJCC, 2018 guidelines.

Cervix Cancer patients – Patients who were tested and diagnosed with Cervix cancer attending Oncology OPD in our respective study settings were enrolled for the study. Their stages were registered by the OPD as per the FIGO staging: Stage 1 to 4 (2009 guidelines) as adapted in the MoHFW guidelines.

Non-cancer participants – Patients who attended Gynaecology OPD for various gynaecological non-cancerous complaints were enrolled for the study

Patient delay – Failure to report to doctor/ physician beyond three months after noticing symptoms in breast/cervix (Bleicher, 2018)

Health provider/ sector delay – Failure to suspect/ initiate the relevant diagnostic test by healthcare personnel, despite strong possibility of malignancy & in situations where patients visit multiple physicians or seek alternative therapy before presenting to a cancer hospital (Mutebi et al. 2020)

Stakeholders included

- Family members of patients included for the study – 6
- Healthcare – District NCD Programme officers, Medical and Surgical Oncologists, Radiologist, Pathologist, O & G physician, PHC Medical Officers, Staff nurses, ANM & NCD nurses and Patient Counsellors – 12

9.8. Instrument

9.8.1. Quantitative – Descriptive study, where a Questionnaire validated by expert was used which contained 7 parts –

- Demographics
- History
- Knowledge, Attitude and Practice (KAP) about Health/ Health Seeking Behaviour
- Access to Health Care Facility
- Knowledge about Cancer
- Knowledge about Cancer Screening
- KAP about Breast & Cervix cancer screening

The questionnaire was applied to both patients and non-cancer participants and was collected before they were enrolled for Qualitative interviews.

9.8.2. Qualitative – Three different structured interview guides were used for patients, non-cancer participants and stakeholders respectively. The interview guide used for patients and non-cancer participants while conducting the Focus Group Discussions (FGD) & In-Depth Interviews addressed the following –

- Awareness and experience about cancer
- Awareness about cancer screening
- Symptom presentation and time duration between diagnosis and treatment
- Family and social support
- Healthcare sector response and patients' experience
- Financial and employers' support
- Improvement in cancer care

The structured interview guide used for stakeholders included –

- Patient's awareness about cancer and its screening
- Lacunae in the existing healthcare system and manpower availability
- Barriers and facilitators for women to access healthcare facility
- Family and social support for patients
- Existing referral system
- Provider role and experiences providing cancer care
- Ways to improve screening and peoples' mobility to screening.

9.9. Data Collection

I. Quantitative method

Structured interview proforma (common for both cancer and non-cancer participants) included seven sections of questions addressing the demographic information of patients, their health-seeking behavior, and their journey to diagnosis and treatment for cancer. The data on socio-demographic information, clinical details, medical history, family history, menstrual history, sexual history, habits, and disease-related characteristics were collected from patients and cross verified with their case sheets. Information regarding their general health-seeking behavior was obtained using a structured questionnaire which included questions addressing their general importance to health, the health care provider they usually visit, their access to the healthcare facility, and information on master health check-ups.

Information on delay in diagnosis was obtained by enquiring them about their date of recognition of symptoms, date and place of health care provider visited, date and place of diagnostic procedures undergone, date of definitive diagnosis and treatment. As much as possible, the date of diagnosis and initiation of treatment were extracted and cross verified with their patient clinical records. All breast and cervix cancer patients who came to the Oncology OPD during the study period were recruited consecutively and interviewed by the Project Officer.

Sources of data were structured interview proforma, patient case sheets and patient's previous clinical records.

Non-cancer participants were also interviewed using the same standardized questionnaire to assess their medical history, family history, and general health-seeking behavior. Questions regarding cancer awareness and screening procedures were also put forth to understand their beliefs, attitude and practices concerning cancer screening and prevention.

II. Qualitative method

The reasons for the delay in health care seeking were explored through focus group discussions (FGDs) and in-depth interviews (IDIs) with both breast and cervix cancer patients. After consent, participants are recruited for FGD. A total of 13 FGDs and 26 IDIs were conducted. The final sample size was decided based on the saturation of information. The interviews were conducted in the local language (Tamil) or English which both interviewer and participant were familiar with.

Health Care Providers (HCP) including the Medical Oncologists (n=2), Surgical Oncologist (n=1), Radiologist (n=1), Pathologist (n=1), O & G Physician (n=1), PHC Medical Officer (n=1), Staff nurse (n=1), ANM nurse (n=1), NCD nurse (n=1), and Patient counsellor (n=1) at the study sites were interviewed.

A total of 10 healthcare providers with different backgrounds were interviewed at various levels of healthcare such as tertiary healthcare setting (urban hospital, n=8) and PHC (rural area, n=1) and the patient counselor was interviewed in the hospital (urban area). In addition, two head of department oncologists were interviewed in the study setting. The health facilities were chosen conveniently within the same district.

The Project Officer (PO), who is a female public health qualified doctor trained in qualitative research methods, conducted the FGDs and IDIs after obtaining the patients' consent to participate in the study. The PO was accompanied by the data analyst and the help staff. The patient interviews were conducted in a separate room adjacent to the OPD to ensure patient privacy and confidentiality. Interviews with HCPs were done at their respective health facility. The participants were informed about the purpose of the study before the interview. Only the participant and the interviewer (PO) along with a note taker (data analyst) were present during the interview. A validated structured interview guide with broad open-ended questions was used to conduct the interview. Interview was recorded both manually and through an audio recording device (after consent). After the interview was over, the summary of the interviews was read back to the participants to ensure participant validation. The data collection was supervised by Principal Investigator (PI).

9.9.1. FGD Method –

Patients and non-cancer participants were grouped according to our recruitment criteria (stage-wise) for each respectively. After collecting the relevant socio-demographic details of all patients in the group, the PO initiated and moderated the discussion. Each group were asked about their awareness about the disease, their opinions about cancer screening, diagnosis, and cancer care. The *active participants* were identified and requested to reserve their thoughts and were later taken up for IDI. All the responses were recorded for transcription and further analysis. Diagnosis and the relevant data were cross verified with the patients' medical records.

9.9.2. IDI method –

One to one personal, in-depth interview was conducted by the PO in the presence of a note-taker, for about 45-60 minutes in a closed consultation room. Two participants from each focus group were selected and interviewed separately. The responses were recorded (after consent) as a sequence of events to form a cohesive story. Cancer-affected patients were probed to open up about their experience with a cancer diagnosis and treatment care and the information received was reviewed at the different stages from the starting point to understand the perception, health-seeking behavior, awareness, conflicts, and challenges. Non-cancer participants were probed to open up about their knowledge, and awareness about cancer, screening procedures, their fears or hindrances to get screened for cancer if any and the information received was also reviewed at different stages of the interview.

Besides, patients' responses, their health records were reviewed and cross-verified for the analysis. All the responses were compiled and coded appropriately to themes to form a cohesive theory.

9.10. Coding, Analysis and Interpretation

9.10.1. Quantitative analysis –

Quantitative data were double entered and validated using EpiData version 3.1 and analyzed using SPSS analysis (IBM SPSS Statistics 17).

Socio-demographic, health-seeking behavior, knowledge and awareness about cancer and patients' clinical presentation were summarized using average mean, median and cross-tabulation. Time duration of delays was summarized using the mean (average) number of days and factors and reasons behind delay were summarised using percentage. The association between delay (more than 3 months following symptom recognition) and socio-demographic and clinical factors were assessed using logistic binomial regression. A 3-month cut-off was used to define delay because there is convincing evidence in the literature indicating that women with delays longer than 3 months have shorter survival compared to women who started treatment within the first 3 months of symptom discovery (30). The measure of association has been presented using adjusted Odd's Ratio (aORs) with a 95% confidence interval (CI).

9.10.2. Qualitative analysis –

Following each interview, transcripts were prepared by the PO and analyst as soon as the interviews were over based on the audio recordings/notes in English language. Manual descriptive content analysis was used to analyze the transcripts (Creswell and Plano Clark, 2007; Kvale, 2007). The transcripts were read and re-read several times by two investigators (JJ and JS) which was supervised by the Principal Investigator and relevant codes were identified which related to the global theme of 'barriers to late presentation'. Similar codes were combined to generate themes using standard procedures and in consensus (Saldana, 2010). Various models were also considered and compared to their factors and reasons behind the delay. Any difference between the two was resolved by discussion or by a third investigator (MR), whenever required (Creswell and Plano Clark, 2007). The findings have been reported by adhering to the 'Consolidated Criteria for Reporting Qualitative Research' (COREQ) guidelines (Tong, Sainsbury, and Craig, 2007). Overall analysis was critically reviewed by

qualitative research experts and their suggestions were incorporated. The themes were then correlated based on the social constructivist paradigm to form a cohesive grounded theory.

Relevant findings from both quantitative and qualitative parts of analysis were then triangulated to ensure theoretical and methodological reflection of information and double validation.

9.11. Ethics Approval

Ethics approval was obtained from the Institutional Ethics Committee of Host Institution – The Tamil Nadu Dr MGR Medical University and other study sites – Kilpauk Medical College and Cancer Institute (WIA) where the study was conducted. Written informed consent was obtained from the participants before the commencement of the study.

10) Study findings

One hundred and ten (110) cancer patients and One hundred and five (105) non-cancer participants were approached, of which, 89 patients and 100 non-cancer participants gave consent and participated in the study.

Socio-demographic and Behavioural Characteristics of participants

The study included patients (n=89) with breast and cervix cancer where more patients with breast cancer were in the age group of 41 – 50 years and mean age (SD) was 49.8 (\pm 9.8) and more patients with cervix cancer were in the age group of 51 – 60 with a mean age (SD) of 54 (\pm 8.26). The patients overall ranged between 28 to 72 years in both sites. The non-cancer participants (n=100) were mostly in the age group of 41 – 50 years and their mean age (SD) was 43 (\pm 7.16).

The mean age (SD) of patients when they were diagnosed with cancer was 49 years (\pm 9.98) among breast cancer patients and 54 years (\pm 8.26) among cervix cancer patients.

Table 10.1 Socio – demographic Information of Participants

Socio-demographic variables		Cancer Patients (n=89)		Non – Cancer participants (n=100) (%)
		Breast cancer patients (n=48) (%)	Cervix cancer patients (n=41) (%)	
Age (In years)	21 – 30	1	-	3
	31 – 40	7	3	39
	41 – 50	17 (35%)	11	44 (44%)
	51 – 60	15	16 (39%)	12
	61 – 70	8	10	2
	>70	-	1	-

Residing Location	Chennai and its suburban	17	18 (44%)	65 (65%)
	Northern TN*	21 (44%)	15	29
	Central TN [#]	5	4	-
	Southern TN [§]	3	2	4
	Outside TN (Andhra Pradesh & Puducherry)	2	2	2
Place of residence	Rural	24 (50%)	23 (56%)	35
	Urban	24	18	65 (65%)
Literacy (Self)	Uneducated	12	19 (46%)	30 (30%)
	Primary school	8	4	14
	Middle school	15 (31%)	14	16
	High school	7	2	22
	Higher Secondary/ Intermediate/ Diploma	3	2	11
	Graduate	3	-	6
	Profession & Honours	-	-	1
Occupation (Self)	Homemakers	28 (58%)	18	50 (50%)
	Daily wage workers	20	23 (56%)	44
	Clerks	-	-	3
	Professionals	-	-	3
Occupation (Spouse)	Unemployed	13	12	37
	Daily wage workers	28 (58%)	29 (71%)	57 (57%)
	Clerks	5	-	4
	Technicians and associated professionals	1	-	2
	Legislators, Senior Officials and Managers	1	-	-
Average monthly income (Family)	Nil	13	5	30
	< 5,000	23 (48%)	23 (56%)	36 (36%)
	5,000 – 10,000	10	10	24
	10,001 – 15,000	1	3	2
	>15,001	1	-	8
Marital status	Unmarried	2	-	1
	Married	38 (79%)	31 (76%)	84 (84%)
	Deserted	6	9	11
	Separated	2	1	4
Consanguinity	Yes	11	23 (56%)	34
	No	37 (77%)	18	64 (64%)
Number of children	Nil	4	-	10
	1	9	5	8
	2	19 (40%)	13	51 (51%)

	3 – 5	15	22 (54%)	31
	>5	1	1	-
Average breast feeding duration (in months)	< 12	11	7	37 (37%)
	12 – 18	25 (52%)	25 (61%)	23
	>18	12	7	26
Underlying medical conditions	Nil	34 (71%)	23 (56%)	65 (65%)
	Diabetes Mellitus	6	12	19
	Hypertension	4	3	8
	Other ailments	4	3	8
Family history of cancer	Yes	13	3	10
	No	35 (73%)	38 (93%)	90 (90%)
Use of contraceptive pills/ barrier	Yes	8	2	4
	No	40 (83%)	39 (95%)	96 (96%)
Age of Menarche	10 – 12	11	6	21
	13 – 16	35 (73%)	32 (78%)	79 (79%)
	>17	2	3	-
Age at first coitus	≤ 18	19	27 (66%)	42
	19 – 35	29 (60%)	14	58 (58%)
Age of Menopause	Not yet	48 (100%)	6	78 (78%)
	≤ 40	-	6	4
	41 – 50	-	23 (56%)	16
	>50	-	4	2

*Northern Tamil Nadu (TN) - Chengalpattu, Cuddalore, Thiruvavur, Kanchipuram, Kallakurichi, Thirupattur, Tiruvannamalai, Tiruvallur, Dharmapuri, Kalpakkam, Salem, Vellore, Krishnagiri, Neyveli, Villupuram

#Central Tamil Nadu (TN) - Nagapattinam, Kumbakonam, Mayiladuthurai, Pudukkottai, Tiruchirappalli, Dindugal.

§Southern Tamil Nadu (TN) - Karaikudi, Sivagangai, Theni, Ramanadhapuram, Tirunelveli, Madurai.

Patients (both breast and cervix cancer) were mostly residing in and around Chennai and the Northern part of Tamil Nadu and when considering rural and urban backdrop, most cervix cancer patients (56%) were from rural parts of the state. Regarding educational qualifications, most patients were either uneducated or attended till middle school, while most non-cancer participants were educated till high school and graduation. The occupation status of patients and their spouses when analyzed, showed that most patients were either homemakers (52%) or daily wage workers (48%) and their spousal occupation was also daily wage labourers. Their monthly income was mostly below Rs. 5,000 or between Rs. 5,000 to 10,000/-.

The stage of diagnosis of patients when cross-tabulated with their educational qualification, most patients who were diagnosed in stage IV of cancer, were found to be either uneducated or attended primary school. Also, those who were daily wage workers (both breast and cervix

cancers) were more commonly diagnosed in their stage IV of the disease. The occupation of the spouse of patients was also cross-tabulated with the stage of diagnosis of patients as they were the ones (in majority of cases) to accompany the patient to hospital visits. Husbands who were mostly daily wage workers were identified as the potential factor for the delay as more patients with husband as daily wage workers were diagnosed at their stage IV of illness and the duration of delay also showed 4 to 9 months, on average.

Their age of menarche on average showed both patients and non-cancer participants attained menarche between 13 to 16 years of age (77%) and very few had attained after 17 years of age. Concerning their marital status, most patients (77%) and non-cancer participants (84%) were married and with regard to consanguinity, cervix cancer patients (56%) had more consanguineous marriage than breast cancer and non-cancer participants. Also, the average number of children bore by 54% of cervix cancer patients was 3 – 5, while breast cancer and non-cancer participants had 2 or less than 2 children. No cervix cancer affected women were childless, while 4 women affected with breast cancer were childless.

The average breastfeeding duration of participants, when assessed revealed that 56% of patients had given breastfeeding for 12 to 18 months for all their children and most non-cancer participants had given for less than 12 months of breastfeeding. The breastfeeding practice of patients with breast cancer when assessed showed that those who had 2 children or less (54%) had fed for an average duration of 15 to 18 months and those who had more than 3 children had fed for an average duration of 12 to 16 months.

The use of contraceptive barriers when assessed showed that most patients had no habit of contraceptive usage, be it pill or barrier and those who had used (9%) were higher among breast cancer affected women.

With regard to their medical history, 65% of both patients and non-cancer participants had no history of any underlying medical illness, and those who had, showed Diabetes mellitus and Hypertension to be the commonest comorbidity among 25 (out of 32) cancer patients and 27 (out of 35) non-cancer participants. Their family history of cancer was also enquired, which showed that 82% of patients and 90% of non-cancer participants had no known family history of cancer. Of those who had a known family history of cancer, 62% still had a delay in diagnosis of their illness and they (patient) were found to be the factor behind the delay. When enquired regarding smoking and alcohol consumptions habits, very negligible to nil participants (both

patients and non-cancer participants) had the habit of smoking tobacco (including smokeless tobacco) or alcohol or have been exposed to passive smoking.

Access to Healthcare and Health seeking behavior of participants

The access to health care and health-seeking behavior of patients and non-cancer participants were assessed based on the presence of government hospital or PHC near their residence, the distance of the health care facility from their household, transport facility, their attitude towards maintaining their health general importance), health care facility and provider they approach during health emergencies. 95% of patients and non-cancer participants had a government hospital or PHC near their residence within 3kms distance. Transport facility to reach the healthcare facility was also feasible and accessible for all participants.

Table 10.2: Healthcare Access and Health Seeking Behaviour of participants

Health Seeking Behaviour		Cancer Patients (n=89)		Non – Cancer participants (n=100) (%)
		Breast cancer patients (n=48) (%)	Cervix cancer patients (n=41) (%)	
Government Hospital/ PHC near residence	Yes	45 (93%)	39 (95%)	94 (94%)
	No	3	2	6
Distance to health care facility (in km)	≤ 3	26 (54%)	25 (61%)	71 (71%)
	4 – 8	14	13	18
	9 – 28	5	3	10
Transport facility	Adequate	43 (90%)	40 (98%)	94 (94%)
	Inadequate	5	1	6
Type of transport	Government	16	22 (54%)	20
	Private (auto, minivan)	10	15	13
	Own vehicle	22 (46%)	4	67 (67%)
General importance given to health	Very important	12	2	24
	Fairly important	33 (69%)	35 (85%)	61 (61%)
	Not important	3	4	15
Healthcare facility approached	Government	16	18 (44%)	53 (53%)
	Private	19 (40%)	12	32
	Self-medication	12	10	14
	Others*	1	1	1
Healthcare provider first approached	Allopath	34 (71%)	29 (71%)	78 (78%)
	Health nurse	1	-	3
	AYUSH physician	-	1	4
	Traditional healers	1	1	1
	Self-medication	12	10	14

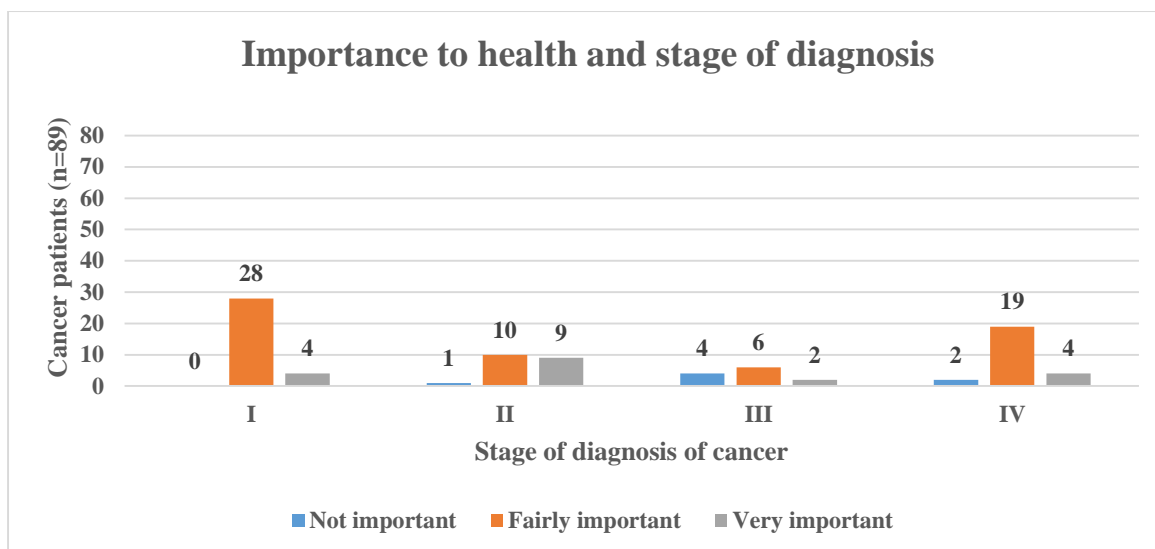
*- Traditional healers, private AYUSH practitioners

To understand the attitude of our study participants towards maintaining their health, we enquired them regarding the general importance they give to their health, where 76% of patients (breast and cervix) reported to have given fair importance to their health, which indicates that they would approach a health care provider after 3 days but within one week of their illness. Among non-cancer participants, 61% have given fair importance to their health. However, 7% of patients and 15% of non-cancer participants have reported that they do not give adequate importance to their health and usually avoid approaching any health care provider even after a week of their illness (any), except in case of acute emergencies.

The health importance given by study participants when compared with their educational qualifications and occupation showed that 29 cancer patients (breast and cervix) who were uneducated had given fair importance to their health while 3 of 29 cancer patients (breast and cervix) who had attended till middle school reported to not have given adequate importance to their health. Concerning their occupation, 39 out of 51 daily wage workers (both breast and cervix cancer patients) had reported giving fair importance to their health, despite their uncompromised work life. Among non-cancer participants, 27 out of 30 uneducated participants reported having given fair importance to their health while among those who had not given adequate importance, 8 out of 15, were educated between middle school to graduation and honors.

The health importance of patients was also cross-tabulated with their stage of diagnosis (Figure 2) and more patients (31%) who had given fair importance to their health, were diagnosed in their early stage of illness (Stage I) and those who had not given adequate importance were mostly diagnosed in their late stage of illness (Stage II, III & IV).

Figure 2: Health importance given by patients and their stage of cancer diagnosis



Concerning the healthcare facility they approach, 38% of patients and 53% of non-cancer participants usually approach government hospitals/ PHC for their health emergencies, while 35% of patients and 32% of non-cancer participants approach private healthcare facilities for their consultations. Also, their healthcare provider of choice was primarily allopath. With regard to self-medication, 25% of patients and 14% of non-cancer participants have the practice of self-medication for their ailments.

When enquired regarding their awareness about master health check-ups and whether they have undergone, 7 among breast cancer patients had known about master health check-ups but only 3 had undergone them and among cervix cancer patients, 3 had known about master check-ups and only 1 among them had undergone. Among non-cancer participants, 26 had awareness about master health check-ups and 17 among them had undergone the check-up.

Knowledge, Attitude and Practice regarding cancer screening

Awareness about cancer screening and its practice was assessed among our study participants by enquiring them regarding their knowledge about cancer and cancer screening, the right age to undergo cancer screening, and whether they had undergone any screening procedures (before diagnosis among cancer patients). Regarding awareness about cancer and its screening procedures, 29% of patients (both breast and cervix) and 72% of non-cancer participants were aware through various media platforms and newspapers. However, among them, only 5 (out of 89) patients (before cancer diagnosis) and 19 (out of 100) non-cancer participants had undergone cancer screening procedures. When enquired about the right age to start/ undergo cancer screening, 47% of patients (both breast and cervix) and 44% of non-cancer participants believed 30 – 40 years of age to be the right age to undergo cancer

screening for breast and cervix. However, 27% of patients and 10% of non-cancer participants had no idea regarding the right age for cancer screening.

Awareness and practice of self-examination of the breast when enquired showed, only 3 breast cancer patients and 26 non-cancer participants were aware and had a prior practice of breast self-examination. Regarding the screening procedures undergone, Breast Clinical Examination (BCE) and Pap smear were the commonest procedures underwent by both patients and non-cancer participants. We also enquired those who had not undergone any screening procedures for the reasons behind, 58 patients and 42 non-cancer participants felt it was not required or unnecessary to get done. This when probed during qualitative in-depth interviews, participants revealed –

“I had no known discomfort or any complaints then and I did not think I should undergo them” – (Stage III breast cancer patient)

“I had no idea what they were doing or going to do and I thought it was unnecessary for me to go and get it done” – (Stage IV Cervix cancer patient)

“I thought if I do something, only then I may get cancer and I live a healthy life, so why go and get yourself checked when you know you are healthy” – (Non-cancer participant)

We also probed those who underwent cancer screening procedures to know what motivated them to get screened and they revealed –

“I heard my office colleagues discussing about how essential it is to get your breast screened for cancer once you reach 40 years of age and wanted to get myself checked as a precaution” (Stage II Breast cancer patient)

“My son motivated me to get checked as he read about the importance of screening for cancer in some social media and he only took me to this PHC where they explained to me the procedure. Though I was really scared, they explained me everything and helped me to get myself checked with ease” (Non-cancer participant)

“I saw about this on TV where a lady doctor said women who have any abnormal signs of bleeding or discharge post menopause should get themselves screened for cancer as prevention. She also explained how much screening can help early detection of cancer and can cure the disease. I immediately thought it was a great thing and the next day I and my sister got ourselves tested” (Stage I Cervix cancer patient).

We also enquired about the awareness of our study participants regarding the HPV vaccine (effective vaccine to prevent cervix cancer) and found that 83 (out of 89) cancer patients and 99 non-cancer participants had no knowledge or awareness about the vaccine.

Delay in Seeking Healthcare, Diagnosis, and Treatment

Breast and cervix cancer patients were questioned regarding the signs and symptoms they experienced before diagnosis, where, when, and how did they get themselves diagnosed, the average time duration between noticing their first symptom and approaching a health care provider, and factors and reasons behind their delayed diagnosis.

The first symptom noticed before the diagnosis of cancer was a lump in the breast (90%) followed by pain for breast cancer patients and bleeding per vaginum (61%) followed by lower abdominal pain and leucorrhoea for cervix cancer patients. 90% of both breast and cervix cancer patients had reported having approached their general physician (private) as their first consultant followed by tertiary care centres. The delay in diagnosis was considered based on the time taken between noticing their first symptom and a healthcare provider confirming their diagnosis and any time duration beyond 3 months was considered as delay (based on strong literature evidence).

Table 10.3: Factor, Time duration and Reason for Delay in Cancer Diagnosis

Variables for delay		Breast cancer (n=48) (%)	Cervix cancer (n=41) (%)	
Type of delay	No delay (\leq 3 months)	13	17	
	Patient delay	32 (67%)	22 (54%)	
	Healthcare delay	3	2	
Time duration of delay (in months)	3.1 – 6	19 (40%)	9	
	6.1 – 9	7	3	
	>9	9	13 (32%)	
Reasons behind delay	Patient	Unaware	29 (60%)	17 (41%)
		Poor family/financial situation	2	-
		Used home remedies	1	-
		Took private treatment with a general physician	-	4
		Advised advanced surgical treatment but did not do	-	1

	Healthcare provider	Misdiagnosed by Private Allopath	1	-
		Mistreated as Lipoma at GH	1	-
		Did not deliver investigation reports (GH)	1	-
		Biopsy results delayed – GH	-	1
		Biopsy results delayed – Private lab	-	1

Factors for delay

The delay was categorized as factors that caused the delay, the average time duration of delay, and reasons behind the delay in diagnosis, and our study reported patient to be the most common factor for the delay. 32 (out of 48) breast cancer patients and 22 (out of 41) cervix cancer patients reported themselves (patient) to be the factor behind the delay and 5 patients (breast and cervix both included) reported healthcare to be the factor for their delay. However, 34% of patients reported no delay as they were diagnosed within 3 months of noticing their first symptom. Though both patient (presentation) and healthcare (treatment) delays were reported in the study, presentation delay was more predominant among all cases.

Time duration of the delay

Thus, the average time duration of overall delay was calculated from the time interval between the date of noticing their first symptom, date of approaching the first healthcare provider, and date when their diagnosis was confirmed. The average time duration of delay was categorized into three-time intervals – between 3.1 to 6 months, 6.1 to 9 months, and above 9 months, based on the mean duration of delay among both breast and cervix cancer patients which was 9 months. 40% (19) breast cancer patients had an average time delay between 3.1 to 6 months and their overall median (Interquartile range, IQR) duration was 180 (68 – 263) days. Among the cervix cancer patients, 32% (13) had an average time delay of more than 9 months since noticing their first symptom and their median (IQR) duration of delay was 150 (30 – 360) days. This when cross-tabulated with their stage of diagnosis, more breast cancer patients who were in late stages (Stage III and IV) during diagnosis, were

diagnosed within 9 months of noticing their first symptom, while most cervix cancer patients were found to be diagnosed after 9 months of noticing their first symptom.

However, in our study, we also attempted to find out the significant time interval that increase the risk of advancing the stage of disease by assessing the average duration taken by our patients between noticing the first symptom and diagnosis of cancer. The average time interval that can be considered as delay in diagnosis and increased the risk of advancing stage of disease showed different time duration for breast and cervix cancer. For breast cancer diagnosis, a time interval of **more than 2 months – OR (95% CI): 5.58 (1.07 – 29.19); p<0.05**) after noticing first symptom increased the risk of late stage of diagnosis while for cervix cancer diagnosis, a time interval of **more than 5 months – OR (95%CI): 3.91 (1.02 – 14.87); p<0.05**) after noticing first symptom increased the risk of advancing stage of disease.

Logistic regression was performed to ascertain the impact of various socio-demographic and behavioral factors of patients on the likelihood that they are the potential factors that would increase the risk of delaying the diagnosis of breast and cervix cancer. The patients who had an average time interval of more than 6 months (based on median duration) in both cases were only considered.

The key factors considered for breast cancer patients were age, education, monthly income, marital status, their family history of cancer, average breastfeeding duration, their general health importance towards health, the distance of health care facility from their residence, and their practice of self-examination. However, the factors which showed higher significance in Hosmer and Lemeshow test (p=0.761) were only taken up for analysis and displayed in table 12.4.

Table 10.4: Potential Risk Factors for Delay in Seeking care, Diagnosis and Treatment among Breast Cancer patients

Factors considered		Time delay (>6 months)	Adjusted OR	95% CI	p value
Age (in years)	< 30	-	3.89	2.2 – 10.38	0.267
	31 – 40	2			
	41 – 50	4			
	51 – 60	4			
	>60	6			
Literacy (Self)	Uneducated	7	2.01	1.54 – 3.12	0.151
	Primary school	3			

	Middle school	3			
	High school	2			
	Higher secondary/ Diploma	-			
	Graduate	1			
Monthly income	Nil	3	3.35	1.75 – 13.34	0.627
	<5000	10			
	5,001 – 10,000	2			
	10,001 – 15,000	-			
	15,001 – 20,000	1			
Family history of Cancer	Yes	2	1.27	1.04 – 3.68	0.098
	No	14			
General health importance	Not important	2	2.09	1.26 – 10.42	0.61
	Fairly important	9			
	Very important	5			
Distance of healthcare facility from residence (in kms)	≤ 2.5	10	1.89	1.29 – 4.75	0.323
	3 – 8	4			
	9 – 15	2			

The logistic regression model was statistically significant, $\chi^2(6) = 13.748$, $p < 0.05$. The model showed 33% (Nagelkerke R^2) of variance in the time duration of the delay and correctly classified 77% of cases. The increasing age of patients (OR 3.89) was found to be associated with an increasing duration of delay in cancer diagnosis followed by the monthly income of patients (OR 3.35) and their general importance towards health.

Similarly, among cervix cancer patients, the key factors considered were age, education, monthly income, marital status, residing area (rural or urban), the average number of children they had, their family history of cancer, their general health importance towards health and the distance of health care facility from their residence. However, the factors which showed higher significance in Hosmer and Lemeshow test ($p=0.41$) were only taken up for analysis and displayed in table 12.5

Table 10.5: Potential risk factors for delay in seeking care, diagnosis and treatment among Cervix cancer patients

Factors considered		Time delay (>6 months)	Adjusted OR	95% CI	p value
Age (in years)	31 – 40	2	3.14	1.78 – 9.66	0.69
	41 – 50	5			

	51 – 60	7			
	61 – 70	5			
	>70	1			
Literacy (Self)	Uneducated	9	2.7	1.73 – 5.97	0.98
	Primary school	3			
	Middle school	6			
	High school	1			
	Higher secondary/ Diploma	1			
Monthly income	Nil	2	1.44	1.11 – 3.58	0.11
	<5000	12			
	5,001 – 10,000	5			
	10,001 – 15,000	1			
Total number of children	1	-	33.7	3.62 – 148	0.01
	2	5			
	3 – 5	14			
	>5	1			
Family history of Cancer	Yes	2	22.5	1.18 – 29	0.44
	No	18			
Residence	Urban	5	1.4	2.07 – 4.96	0.17
	Rural	15			
General health importance	Not important	3	1.24	1.02 – 7.04	0.17
	Fairly important	16			
	Very important	1			
Distance of healthcare facility from residence (in kms)	≤ 3	12	3	1.44 – 26.15	0.86
	4 – 8	6			
	9 – 28	2			

The logistic regression model was not statistically significant, $\chi^2(8) = 13.31$, $p = 0.1$. The model showed 37% (Nagelkerke R²) of variance in the time duration of the delay and correctly classified 63% of cases. More number of children bore by a woman (OR 33.7) was found to be associated with an increasing duration of delay in cancer diagnosis followed by family history of cancer (OR 22.5) and their increasing age.

Reasons behind the delay in diagnosis

Both breast and cervix cancer patients who reported delays in their diagnosis for cancer were enquired regarding the reasons behind the delay. Most patients (both breast and cervix) reported their poor awareness about the disease and its signs and symptoms (52%) to the main

reasons behind their delay (Table 12.3). However, those patients who had reported healthcare to be the causative factor for their delay stated misdiagnosis and delayed investigations reports to be the predominant reasons for their diagnostic delay.

Out of 24 in-depth interviews (age 30 – 70 years; 70% in advanced stage of disease) conducted among patients, their reasons for the delay in diagnosis were probed and their responses were classified based on factors as –

- (i) Reasons for patient delay
- (ii) Reasons for healthcare delay

(i) ***Reasons for the patient delay –***

Incomprehension about disease

I felt hardness in the breast initially but it was painless. After two months, when it did not get normal, I thought it should be checked up (Breast cancer patient, 40 years)

There was watery discharge from my nipple with pain for the past 3 months, where if I pinch out the water, the pain will subside. I also asked an old granny near my house regarding the discharge from nipple. She suggested to me it was bad water in the breast and should pinch it out. So I did not think of visiting a doctor (Breast cancer patient, 46 years)

Initially, the only lump was there, pain started later. Maybe the lump must have been for quite some time but I did not see. While feeding the baby, when I saw some difference in breast and touched, found there was something round like a lump (Breast cancer patient, 48 years)

I had discharge mixed with blood for 3 – 5 months and some colour with foul smell, then I went to the doctor for the check-up. There they took all the tests and finally diagnosed I have cancer (Cervix cancer patient, 50 years)

I had bleeding on and off for nearly 5 years. I thought it was normal after menopause and left without checking. Last year, I started sensing discharge and it was foul-smelling. Only then I thought something was wrong and got checked (Cervix cancer patient, 60 years)

Lack of knowledge/ awareness

I had no idea about the lump. One day I couldn't wear my sari blouse as it was too tight, so I wore a nightwear. Only then I noticed there was a lump. I saw some differences 4 months back (Breast cancer patient, 65 years)

I did not feel any sign or symptom, this lump must have been present for the past 6 months (Breast cancer patient, 46 years)

I had lump in my breast, thought it was fat globules so I kept hot external applications like coffee tumbler. Later, it became reddish and swelling increased in that area. Outside it was seen well. I was very foolish I should have noticed (Breast cancer patient, 56 years)

I noticed lump in my breast 5 years back but left unattended as I had to go to work to support my family. I thought it was solidified breast milk and will reduce (Breast cancer patient, 45 years)

I had frequent bleeding complaints but left it carelessly and after that one day, I had severe pain and bleeding, after that, I went to our nearby hospital and they confirmed cancer. I had no idea (Cervix cancer patient, 63 years)

Most patients have very poor knowledge about disease, especially the rural side where they fail to notice any symptoms and do not approach any HCF till it disturbs their daily routine (Medical Oncologist, Tertiary care)

Laxity/ Lethargy

There was a lump in my breast for 6 months and I noticed it. But I didn't care then because I was busy with my work. Only when the size started increasing, I came for a check-up (Breast cancer patient, 61 years)

I was very careless then, I left it alone for 8 months and the intensity of pain increased too much. Only then I took a scan at a private lab. They suspected and asked me to go to a cancer hospital (Breast cancer patient, 37 years)

I visited a hospital with my neighbour for her check-up and the doctor checked me and advised me to take some tests for my bleeding problem, but I didn't go for 2 months because we had our cousin's wedding that month (Cervix cancer patient, 56 years)

I had white discharge for months and it was very foul-smelling, it was dust coloured. I did all home remedies and continued to work as I did not think it was important (Cervix cancer, 54 years)

They don't think it is necessary or believe that it is unnecessary to get tested. Also, they are ignorant about what they will be doing or why they should get tested in the first place (Surgical Oncologist, Tertiary care)

Fear of disease

I fear this disease and I don't watch TV or even hear someone talk about cancer. If I had known about this, I would have come earlier (Breast cancer patient, 47 years)

Don't know anything about it, but hearing it, gives me fear. So I avoided even watching TV when something regarding this comes up. I will not listen also about this disease (Cervix cancer patient, 57 years)

Most women, even after suspecting they might have acquired cancer, don't go for confirmatory diagnostic procedures due to fear of acknowledging the disease. They will get tested only after their symptoms become worse or becomes intolerable (Head nurse, Medical Oncology ward, Tertiary care)

Ignorance

Doctor said that the symptoms must have been there for more than a year and I may have ignored them (Breast cancer patient, 56 years)

Mostly, lack of awareness and confidence from the patient side, and due to that there is ignorance. Mostly, breast cancers have painless lumps, patients usually ignore that, but pain occurs only when there is an infection, patient doesn't know that (Medical Oncologist, Tertiary care)

Lack of knowledge about whom to approach

I went to a private scan centre to take a scan and another centre for biopsy. I did not know who to approach and did not have enough money, so waited for a month, later some known people there, suggested me to visit this hospital (Breast cancer patient, 56 years)

Regarding screening/diagnosis, I believe patients and general public are interested to get themselves tested but they have no idea where to go, what type of tests will be conducted and how long will they be held in the centre (Patient Counsellor, Tertiary Oncology ward)

Poor care/family support

No one to take care of me as only I and my sister are here. She goes to work and only with that money, we live. So no one was there to take me to hospital (Breast cancer patient, 65 years)

I told about this lump to my husband, he said it will be some normal lump and will reduce. My sister only took me to hospital and cares about me. My husband just asks if I am fine (Breast cancer patient, 56 years)

I have self-examined my breast and informed about small lump in my breast to my husband. He didn't care about it and told not to go hospital for this unnecessary reasons. He is a drunkard person and if I go to hospital I should take leave and my daily wage will be cut for the day. If I don't give money for his drinks he will quarrel with me. So I ignored the symptoms and went to work for the welfare of my children (Breast cancer patient, 46 years)

Women who rely on their husbands to take them to hospital usually delay as they will be mostly daily wage labours and will delay due to their work schedule (ANM nurse, Urban PHC)

Ignored by family

My husband cursed me saying I got the disease because of some sin I had committed. I had always taken care of him well during heart operation. I even neglected my complaints (Breast cancer patient, 56 years)

My husband would fight with me daily regarding this, he wouldn't even accompany me to hospital (Cervix cancer patient, 39 years)

My sister is helping me financially. My both sons left me alone after hearing their wife's advice (Cervix cancer patient, 63 years)

Delayed due to poor finance

I did not have enough money to get treated in my hometown. I waited and got some finance and I came here (Breast cancer patient, 42 years)

Later, I had shoulder pain so I went to a nearby hospital. They asked me to take an MRI scan which cost 25000. I did not have money to spend so I did not undergo a scan (Breast cancer patient, 45 years)

Treatment delay –

I went to a private hospital for check-up and they asked for 2 lakhs for treatment. I did not have money so I couldn't start treatment immediately (Breast cancer patient, 53 years)

In a private hospital they diagnosed the cancer and for treatment they demanded 7 lakhs. I explained my financial situation but they did not say anything. I had no idea where to go (Breast cancer patient, 46 years)

(ii) Reasons for healthcare delay

Poor communication

I had gone to many doctors in Vellore, but no one really told me about this cancer. They gave some treatment but pain did not reduce (Breast cancer patient, 47 years)

I had pain in my breast and went to this government hospital, where they prescribed some injections and said the pain will reduce. But it did not reduce and when I went again, they took a scan and said it was nothing but some skin complaint which will reduce normally. But after 3 – 4 days, lump increased in size and when I went there again, they said nothing and gave an injection. The pain got worse (Breast cancer patient, 44 years)

They took a scan and said there is a tumor but nothing about cancer, then we went to another private hospital, they did a hysterectomy, then they sent us home, but I still had some abdominal discomfort (Cervix cancer, 45 years)

Missed Opportunity/ Misinterpretation

The lump was there for the past 1 month and I went to a nearby private hospital where they took biopsy and after the results, they said it was some skin related lump, not cancer. So need not worry about it. After 6 months I had pain in the same breast but the lump was at another place. So, they confirmed it has cancer after biopsy results (Breast cancer patient, 47 years)

When I was feeding my baby, I found a lump in my breast. I thought it could be because the milk got solidified. I even went to a Government hospital for a check-up. They told it might be some skin related lump and asked to keep hot water bag externally (Breast cancer patient, 37 years)

I went to private hospital they took all the reports but didn't tell me diagnosis and then came to government hospital (Cervix cancer patient, 67 years)

I went and checked near private clinic, that doctor examined and advised me to remove uterus and did hysterectomy operation, after that I left as I did not have bleeding. After some days, I started having bleeding, then one doctor referred me here and found that I have cancer (Cervix cancer patient, 72 years)

Inappropriate/ Wrong treatment

I noticed a lump in my breast and went to a nearby government hospital, where they gave rock salt treatment for a week and said if I do exercise, the lump will reduce. But the size increased than before and became worse. They did not take any scan or test before treatment (Breast cancer patient, 52 years)

They asked about my complaints and gave one injection/syringe, after using that I again got bleeding, they again gave injection. Later I went to another hospital where they diagnosed cancer (Cervix cancer patient, 65 years)

They did examination and told while examination, it's bleeding, that might be sign of cancer, then they gave medicine but said nothing. So I took it and left for 3 years, then again started with same complaint and came here, they diagnosed that I have cancer (Cervix cancer patient, 39 years)

Some general physicians who are not trained in cancer treatment or care might miss a case or two, which is definitely not intentional. In most cases, we try to give them best first aid care and refer them to a multispecialty tertiary care for better care (PHC Medical Officer, MBBS)

Delayed reports

It nearly took a month to get the report. We waited but got no information from the lab (Breast cancer patient, 45 years)

The test schedules are quite long and no treatment has been started yet. They are making us wait for days to conduct tests (Breast cancer patient, 41 years)

They took some tests and when results of 2 tests came, they said they can confirm only after another two test results. I took nearly 1 month to confirm cancer (Breast cancer, 37 years)

I didn't get medical reports from a government hospital, so went to private hospital where they took another month to give the results and then with the reports, we came to government hospital (Cervix cancer patient, 63 years)

Delayed treatment due to finance

Later we went to a private hospital for treatment but to operate, the doctor demanded Rs 50,000. When we said we had government insurance, the chief doctor did not accept the

insurance saying the claim process will be delayed. Took 1 month and asked us to come every day to finally say he will not take the case (Husband of the Breast cancer patient, 51 years)

Barriers and Facilitators for early diagnosis

We enquired our patients and non-cancer participants during our Focus group discussion, regarding what are the existing barriers for early diagnosis of cancer or for approaching a healthcare provider and what could be the facilitators that could have helped them to undergo screening and early diagnosis. Patients had stated that –

“My fear for cancer was my biggest barrier which stopped me from learning about the disease. If I had the courage to learn, I would have figured out my symptoms sooner and would have approached proper tertiary care” (Breast Cancer patient, 56 years)

“Being in the village, all we know is get up, do household work and go to farmland for daily work. We had no idea about this cancer or screening or even where to go for a check-up for that matter. If the healthcare nurses and doctors who regularly visit us had informed, we would have listened and I would have got tested” (Cervix Cancer patient, 65 years)

“Can explain it to people like me. Explain the things, its importance and procedures, so everyone would go and check” (Non-cancer participant, 40 years)

“Have to encourage all our neighborhood to go for screening. If they are not getting regular periods, have to ask them to go screening, it could be due to thyroid or cancer or anything” (Non-cancer participant, 46 years)

We also interviewed stakeholders of various positions and backgrounds to understand their opinions on cancer screening and barriers and facilitators for early cancer diagnosis. Many of them had revealed that patients are either unaware of what will happen during screening tests or have this fear of acquiring cancer only when they undergo screening. Their statements were –

“They are either unaware or feel shy to reach out to a hospital or screening camp. They need support from their family like husband and children who can educate them and bring them for screening or testing effortlessly. They also should develop the thought that they should care themselves too” (Matron, Rural Tertiary Oncology ward)

In order to reduce the duration of delay, diagnostic test reports for cancer suspects should be given priority to ensure early confirmation. For FNAC, mostly it would take 24 hours and in

case of any doubt with the need to correlate clinically, that might take another 2 days. For biopsy, it would take at least 5 days and 5th day should be ideal to give result. Even in case of any holidays in between, it might get delayed, but should take between 5 days to 1 week” (Pathologist, Rural Tertiary care).

“One way to raise awareness in society is by improving awareness among school and colleges. We conducted an awareness program in a private college near chrompet. In that college we did awareness session and many people raised questions about the clinical presentation of cervical and breast cancer. It was a good awareness section and like a follow-up of that, many students brought their mothers for check-up to our centre. So this would be the best way in improving awareness among people. Also, compulsory Master check-up among young teens in colleges and schools can help with early detection of cancer” (Director of Radiation Oncology, Tertiary care)

“The number of camps should be increased and conducted area wise, to cover the target population. Also need to reduce their time spent at camps by increasing the manpower to make more number of appointments. Need for manpower is also a barrier for most working women who couldn’t afford to wait for a whole day at a screening camp” (PHC Medical Officer, MBBS)

11) Significance of the study results

This study is based on the mixed-method design where a sequential explanatory method was employed by conducting the quantitative part of the study followed by a qualitative approach, to assess and understand the reasons behind the delay in diagnosis of breast and cervix cancer. The study also included non-cancer participants for both parts of the study to understand their health-seeking behavior and their opinions on cancer screening, as they are the representative of the target population who may be at potential risk of acquiring cancer.

Socio – demographic and behavioural characteristics

The socio – demographic and behavioral characteristics of patients, both breast and cervix cancer showed that most patients belong to the age group of 40 to 60 years with a mean age of 50 and 55 years for breast and cervix cancer respectively. As per various literature evidence, it is strongly reported that women above 40 years of age are highly vulnerable to acquiring breast and cervix cancer and our study reports show strong agreement to them.

The educational qualification of participants in our study was reported to be in low level with more number either uneducated or attended till middle school, but the non-cancer participants included, were mostly between attended high school and graduate and honors. This is similar to various study reports suggesting that lower educational qualification is a high risk for cancer. The occupational levels of patients (before their diagnosis) when assessed showed that most patients were either homemakers or daily wage workers and those who were diagnosed in their later stages of disease were mostly daily wage workers. When we probed more about the situation during our in-depth interviews with various stakeholders, we could find that daily wage workers were indeed more compromised with their health and have less screening rates because of their poor affordability for wage loss at work.

“Women, especially in the lower and middle-income community are usually daily wage workers and they cannot afford to spend a day in the healthcare facility for any test or screening procedures as they will lose their wage for the day” – Patient Counsellor, Tertiary Oncology care.

Also, those women who were homemakers still faced a delay in their diagnosis as they were hesitant to visit a healthcare facility on their own and their husbands were daily wage workers who couldn't afford to take leave for a day for a check-up. This shows the need for women to step themselves up to visit a healthcare facility for their good is still existent and build their health-seeking behavior for their betterment. Also, most patients in our study belonged to low and lower-middle-income households and that has been a hindrance to a majority of people to approach a healthcare facility for a screening or diagnostic test or a master health check-up as a means of prevention.

Concerning the marital status of our patients, most women in all three groups considered were married and yet few affected with breast cancer and among non-cancer participants were unmarried. As various literature studies suggest that staying unmarried or nulliparous women are at high risk of acquiring breast cancer and our study also confirms the facts. Also, the number of children bared by a woman, on average, was higher among cervix cancer women than breast cancer women, confirming the fact that multiparous women are more exposed to the risk of cervix cancer. With regard to breastfeeding, the average breastfeeding duration of our study participants was between 12 to 18 months which is the normal advised duration. However, poor breastfeeding duration is a risk factor for breastfeeding and our study

contradicts this fact stating that normal duration of breastfeeding is not a protective factor against breast cancer and those women are also exposed, though in lesser proportion.

The family history of cancer is a major risk factor as cancer is a hereditary disease and our study participants also reported that few of them had a family history of various cancers. This when compared with their stage of diagnosis, to test whether their family history probed them to be more aware of the clinical signs of cancer, more women who had family history were diagnosed in the early stages of the disease. This shows the importance and impact of first-hand information regarding diseases like cancer in early detection and diagnosis. Another interesting finding was, those women who had a delay in their cancer diagnosis were found to be the factor behind the delay. This shows the lack of understanding about the disease. Also, strong literature findings suggest that the presence of comorbidities might be a triggering factor for cancer and our study partially lines with the fact as 36% of patients only had some underlying medical conditions, predominantly Diabetes and Hypertension.

Access to Healthcare and Health seeking behavior

On assessing the health-seeking behavior, their knowledge regarding the availability of a government healthcare facility (HCF) near their residence and their attitude and practice towards maintaining their health were considered for analysis. 95% of our study participants (both patients and non-cancer participants) were aware of the availability of an HCF near their residence and the average distance of the HCF from their residence was also less (within 3 km). The attitude and general importance given by our patients and non-cancer participants towards their health were determined by the number of days they take, on average, to approach an HCF in times of distress. 60 to 80% of our patients and non-cancer participants reported approaching an HCF within 3 to 7 days of their illness indicating fair importance to health. This, when assessed in comparison to their educational qualification, patients who were uneducated, reported being more conscious of their health than others, while among non-cancer participants, those who attended till middle school and high were more conscious of their health in comparison to those who were uneducated. This when also compared with their occupation, more patients who were daily wage workers reported to give fair importance to their health in comparison to those who were homemakers. The general importance given by patients to their health when compared with their stage of diagnosis, more patients who had given high and fair importance to their health were more diagnosed in early stages of illness (Stage I) and those who reported to not have given adequate importance to their health, were more diagnosed in

the later stages of disease (Stage II, III and IV). This explains the need for education on the importance of healthcare and its maintenance among women to ensure the early diagnosis of diseases like cancer.

When enquired regarding the first healthcare provider they usually approach, 71% of patients and 53% of non-cancer participants usually prefer to approach an allopath for their consultation. While a smaller section of patients (20%) and non-cancer participants (14%) had the habit of self-medication for their illness. This when compared to their stage of diagnosis, more patients who had self-medication habits and those who approached traditional healers were more diagnosed in their later stages in comparison to those who approached a qualified healthcare practitioner or a tertiary healthcare facility.

The knowledge, attitude, and practice of cancer and its screening procedures was assessed among both patients and non-cancer participants, which showed that both groups had very limited knowledge regarding the disease or its screening procedures. The number of patients who had undergone screening before the diagnosis of cancer was less than 10% in both groups. This aligns with the recent NFHS V (2019 – 21) which shows that the percentage of women including both rural and urban areas who had undergone screening for breast and cervix cancer were 5.6% and 9.8% respectively (10). Among the non-cancer participants, only 19% had undergone screening procedures for breast and cervix cancer, despite their regular visits to the gynecology OPD for other ailments. Also, the percentage of women who had/have the practice of self-examination of the breast was 6% among breast cancer patients and 26% among non-cancer participants, despite increased health education on the subject. The reasons for this poor response to screening when probed during our in-depth interviews, most patients had stated that –

“Didn’t have any interest in knowing what cancer is” – Stage I Cervix cancer patient;

“No, don’t know where the screening will be done, I didn’t have time for doing them” – Stage II Cervix cancer patient.

When we probed the stakeholders during the interview, an O&G physician stated that

“Because many feel it’s not necessary, and more of wait time and poor awareness. Also, there is still stigma existing to approach a cancer screening camp or center among people, especially in rural areas”

However, when non-cancer participants were interviewed regarding their cancer screening knowledge and practice, few people had regular self-examination practice and previous history of cancer screening. When probed on what motivated them towards screening, they had stated that –

“I have heard it from the TV while coming to the government hospital, also seen posters here which educate about cancer. So I thought being in the age above 40 years, I should get checked too”

These findings partially represent the concepts of the Health Belief Model (31) which is used to understand the health-seeking behavior of people and provider health promotion towards screening for early detection and diagnosis of diseases. Various patients in our study, when enquired regarding what do they think to be the reason for acquiring cancer and they had stated that –

“Only those who use tobacco, alcohol and have poor lifestyle habits usually acquire cancer. I live a healthy life and that is why I did not even think of getting tested for cancer. So I don't know what could be the reasons”

This falls under the construct of Perceived Susceptibility in the Health Belief Model where patients have their subjective perception of the risks for acquiring the illness.

Thus, though health education is increasing and omnipresent among people, there is still a lack and need for education to eliminate stigma among people regarding cancer and its screening procedures, and a clearer explanation is still needed to improve screening response among the general population. Also, the issues of increased waiting time need to be taken into consideration to ensure more working women (including daily wage workers) get covered.

Also, there is a need for increased awareness on HPV vaccines, their purpose, and their efficacy against cervix cancer as most patients and non-cancer participants were unaware of the vaccine.

Delay in Seeking Healthcare, Diagnosis, and Treatment

The delay in cancer diagnosis was categorized primarily based on the time duration of delay, that is, any time interval beyond 3 months from noticing the first symptom was considered to be delayed and 66% of patients had delayed diagnosis due to various reasons and factors. The primary factor for the delay was patients themselves (91%) followed by healthcare delay. The patient delay was attributed to various reasons, predominantly due to their poor knowledge or

awareness about signs and symptoms of cancer and the healthcare reasons of delay were misdiagnosis and delayed diagnostic reports.

Regarding the time duration of delay, most breast cancer patients were diagnosed between 3 to 6 months of noticing their first symptom while most cervix cancer patients were diagnosed beyond 9 months of noticing their first symptom. The key factors considered to be a potential risk factor for diagnostic delay in breast cancer were age, education, monthly income, family history of cancer, their general importance to health, and distance of HCF near their residence. The regression results showed that increasing age was a predominant risk factor for delay in diagnosis. This is similar to the systematic review conducted by *Rivera-Franco and Leon-Rodriguez 2018*, which explored the association of socio-demographic factors such as age, education, marital status, occupational status, and socioeconomic status with presentation delay (PD) in breast cancer patients. Advanced age of patients was the only socio-demographic factor that seemed to be strongly associated with PD (32).

Among cervix cancer patients, the residence of patients and the total number of children they had bared were also considered in addition to other socio-demographic and health-seeking behavior factors and the increased number of children turned out to be the predominant risk factor for delay followed by their family history of cancer.

Also, when assessing the significant time interval that increased the risk of advancing the stage of disease, the average time interval that can be considered as delay in diagnosis and that increased the risk of advancing stage of disease showed different time duration for breast and cervix cancer. For breast cancer diagnosis, a time interval of more than 2 months (OR: 5.58 (1.07 – 29.19); $p < 0.05$) after noticing first symptom increased the risk of late stage of diagnosis while for cervix cancer diagnosis, a time interval of more than 5 months (OR: 3.91 (1.02 – 14.87); $p < 0.05$) after noticing first symptom increased the risk of advancing stage of disease. This finding differed from major studies which suggested a 3-month delay to be a significant time interval for advancing disease (15). This indicates that patients' appraisal of symptoms in breast cancer are quite delayed and any delay beyond 2 months clearly poses the risk for advancing stage of disease. Also, among cervix cancer patients, appraisal of symptoms need to be earlier for detection for cancer within 5 months as any delay beyond that duration, poses risk of advancing stage.

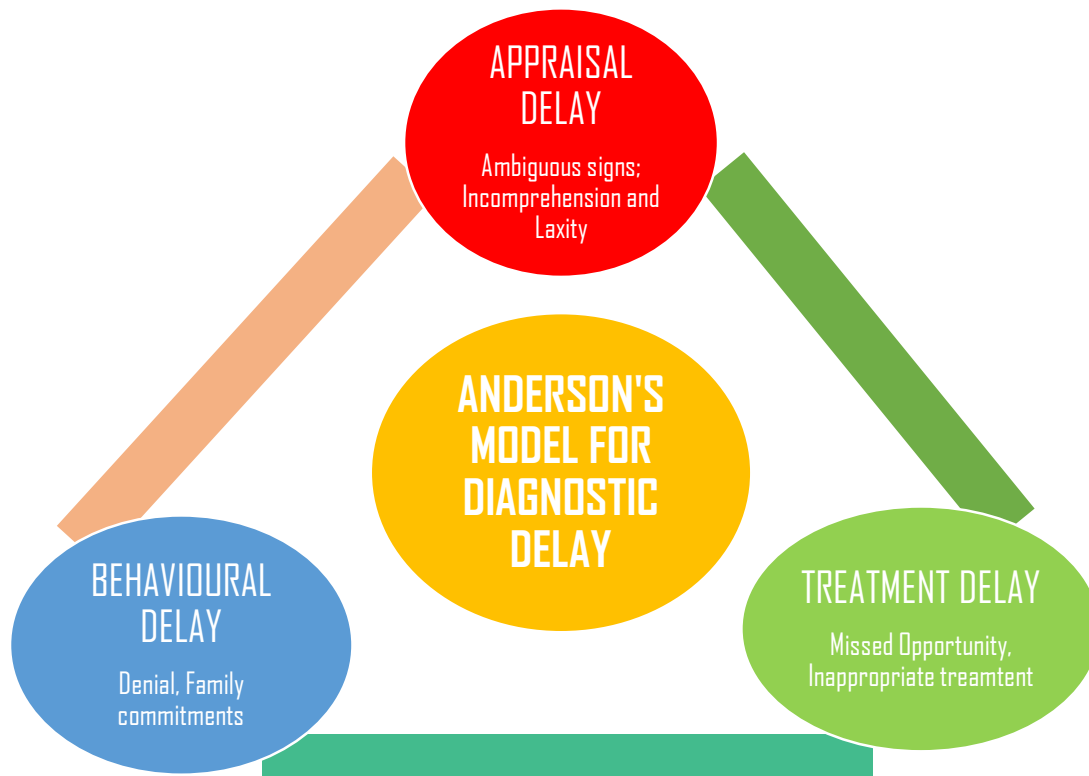
When probed the reasons behind delay during in-depth interviews, more patients had stated that they had either not noticed the lump or had noticed yet had no idea that it would be

cancerous, in cases of breast cancer. While in cervix cancer, patients had stated that they had thought that the bleeding they had was post-menopausal and did not think it to be a disease concern.

These findings represent Anderson's model of diagnostic delay (33), where five categories of delay are included. Our study findings represent the appraisal, behavioral, and treatment delays (Figure 3), where appraisal delay is more predominant than the others. Appraisal delay indicates that delay caused by the patient due to non-recognition of the seriousness of symptoms. This non-recognition in cases of diseases like cervix cancer is quite common (as per various literature studies) as the symptoms are usually similar to menopausal bleeding and the clinical picture remains ambiguous. While, in cases like breast cancer, this delay is quite uncommon, as the clinical signs are quite evident, for example – a lump in the breast. However, our study had reported unique findings that a greater number of patients, had stated that they were unaware of the lump or had noticed yet thought it was some normal anomaly that will recover on its own. This falls under the non-recognition of the seriousness of symptom or disease and thus, this type of delay is undeniably appraisal.

Few breast and cervix cancer patients have also stated that though they had noticed symptoms, they hadn't approached a healthcare provider and the reason behind that was their belief that the symptom was normal and they would not acquire a disease like cancer. This clearly falls under behavioral delay, where patients live in denial regarding the clinical picture of disease and delay approaching a healthcare provider. Some patients have also delayed approaching a healthcare provider for 2 months due to marriage in their family. This also falls under behavioral delay where patients had found a reason to postpone medical consultation.

Figure 3: Anderson's model of diagnostic delay



Another category of delay was also observed in our study, that is, treatment delay, which attributed to the reasons behind healthcare delay, informed by our study participants. Patients who had approached a healthcare provider, in some cases, stated that they had missed the opportunity of complete examination and diagnosis of the case and exhibited a superficial attitude towards it. Patients who had reported healthcare as the factor for their delay in diagnosis had stated that they were not clearly explained of the condition before advising for diagnostic tests or were given treatment with no proper communication for months. Few breast cancer patients also stated that they were informed that the lump they had noticed was nothing but Lipoma (non-malignant condition) and were not advised for any treatment. Also, those who had cervix cancer, reported that they were advised for advanced uterus surgery and some had even undergone the surgery, without any confirmatory diagnosis for cancer and were not advised clearly on post-operative care. Those patients mentioned to have experienced symptoms even after the surgery and were eventually diagnosed with cancer in advanced stages.

Barriers and facilitators for early diagnosis

Early diagnosis or diagnosis within 3 months of noticing symptoms is highly essential to ensure effective treatment, good prognosis, and improved quality of life. This can be ensured by addressing various issues involved with delayed diagnosis in both patients' and healthcare

sector factors. From the opinions of various patients and stakeholders, the commonest barriers for early diagnosis were –

- Lack of knowledge or awareness about the disease
- Incomprehension of people regarding the clinical picture of cancer (both breast and cervix)
- Misconceptions, fear and social stigma regarding regular check-ups and screening, especially in rural areas.
- Inadequate number of cancer screening camps and manpower in screening camps
- Inadequate knowledge among people regarding which healthcare provider to approach.

The facilitators that would enhance the existing system of approach and early diagnosis of cancer cases stated by our study participants and also quoted in various literature studies include –

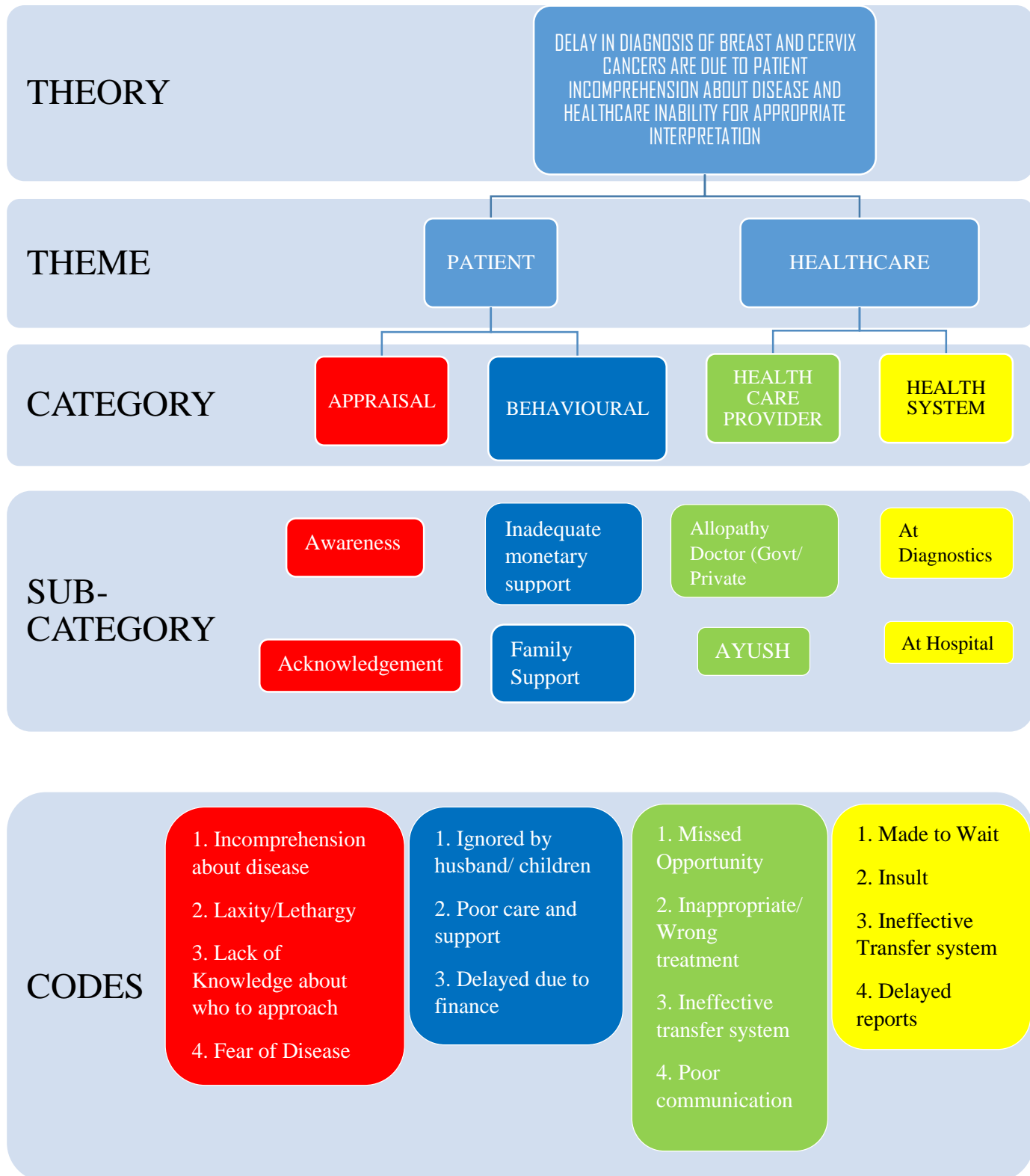
- Promoting self-examination through female health workers for breast cancer,
- Opportunistic screening at health facilities,
- More screening camps in the workplace and periodically conducted by management.
- Patient-friendly gender-sensitive screening,
- Enhanced role of women support groups where they can openly discuss such sensitive issues (20).

12) Conclusion

As per our study findings, delay in diagnosis of common cancers among women, especially breast and cervix were most commonly reported to be due to lack of adequate knowledge and awareness regarding cancer and its clinical signs and symptoms. The factors and reasons reported in our study when coded and analyzed, separated into categories followed by themes based on a constructivist paradigm which then evolved into a cohesive grounded theory. The mixed-method approach of the study correlated in its findings where the delayed diagnosis of breast and cervix cancer patients were expressed based on their time duration of delay in numbers and percentage which when followed by a qualitative approach, owed various in-depth explanations behind the reasons for the delayed time interval for approaching a healthcare provider or for diagnosis. They were then categorized into sub-categories and main categories in line with various qualitative research models like Anderson's model for the delay

in diagnosis. These categories separated into two different themes which raised to one theory. The paradigmatic presentation is explained in Figure 4.

Figure 4: Grounded theory presentation



Various statements revealed by patients and stakeholders when coded appropriately fell into eight subcategories –

- 1) Delay due to awareness/acknowledgment of signs and symptoms
- 2) Delay due to inadequate monetary support or poor family support
- 3) Delay due to healthcare provider (government/private/AYUSH)
- 4) Delay due to diagnostics or at hospital

The main four categories that were derived out of these sub-categories were the prime causative factors for the delay –

- I) Appraisal Delay
- II) Behavioral Delay
- III) Healthcare provider Delay
- IV) Health system Delay

These categories pointed to two main themes behind the reasons for the delay in diagnosis and they are –

- ❖ PATIENT
- ❖ HEALTHCARE

Analyzing these two major themes, we derived out a theory that –

“Delay in Diagnosis of Breast and Cervix cancers are due to Patient Incomprehension about the disease and Healthcare Inability for Appropriate Interpretation”

A research hypothesis also emerged out of the study that –

“Patients who gave adequate importance to health and have had cancer screening have more probability of an early diagnosis of breast/cervix cancer”

This hypothesis can be tested using large-scale studies in the future.

There were a few limitations in this study. First, patients had challenges in recalling information related to their first experience of symptom recognition and the health care providers visited. However, primarily the dates related to diagnosis and treatment were corroborated from available clinical records. Second, social desirability bias might have crept in as the patients might respond favorably to questions related to their delay in the first presentation and the first health care provider visited. Third, the study participants were

initially quite hesitant to attend focus group discussions as they did not want to interact with fellow cancer patients or share their experiences. However, the moderator made the patient comfortable to express themselves. Fourth, this study only included those patients who reached the tertiary care centers in the urban study setting to receive cancer care excluding those who died or those who did not receive appropriate care for breast cancer. Fifth, in this study we did not collect the patient's journey through different health care providers before, during, and after diagnosis was not completely focussed and may have missed some relevant data.

13) Recommendations

The recommendations to reduce delay in diagnosis and promote early detection of cancers among women based on the study findings are –

1. Awareness regarding the importance of screening in the early detection of breast and cervix cancer can be promoted among college-going under graduation students. This is because the mothers of these young adult population will be in the potential age group at risk of getting breast/cervix cancer and thus the targeted age group for health promotion. They can be educated on the need to undergo screening and can be encouraged to take their mothers for screening tests.
2. The importance of regular screening for breast and cervix cancer and its impact on early detection can be educated through promotional videos where two comparing corresponding scenarios of women undergoing early and late detection of cancer and their experience and journey through the process of treatment and post-treatment quality of life.

The promotional health education videos, though are plenty for diseases especially cancer, videos to promote screening or regular check-ups for early detection are very less. A video explaining two scenarios - where one woman has regular self-examination practice and gets herself regularly screened for cancer, who noticed some change in her breast and got herself tested for cancer which was in early stage. She took up treatment at an appropriate time in specialized care and got herself cured. The second scenario shows a woman who does not have any knowledge or awareness regarding cancer screening and had experienced some early-stage cancer symptoms. She left them unnoticed carelessly and cancer advanced to late stages. She was under treatment even after 2 years and eventually experienced poor prognosis. This could pique the interest

of women to understand the importance of cancer screening and can be advertised through all media platforms and in primary to tertiary care OPDs.

3. State-wide screening camps can be conducted all through the year for both breast and cervix in every part of the state, instead of just one month a year (example – October for Breast cancer awareness). All through the year, the promotion of cancer screening will ensure no woman in targeted age group is left out or left unscreened and this will also relieve the time constraint for working women.
4. Exclusive centre for cancer screening can be established inside the premises of all tertiary care hospitals in order to identify potential cancer suspects and ensure immediate follow-up on diagnosis and treatment care.
5. Exclusive female healthcare personnel (eg. Healthcare nurses) can be appointed at screening camps to sensitise people on the importance of screening and early detection and coordinate potential suspect cases for regular follow-up to nearest referral centres by tracking using their contact details.
6. Adequate training for general practitioners and nurses at primary referrals on cancer screening and early clinical presentation of breast and cervix cancer can be given to avoid any misdiagnosis and ensure early detection.
7. Active engagement of VHNs to facilitate in raising awareness, identifying suspects and promoting effective referrals during door-to-door visits.
8. Grass root collaboration with Community-based NGOs to educate and motivate general people on the importance of breast self-examination and cancer screening (specific to breast and cervix) and regular surveillance on whether women above 30 years of age had undergone screening tests.
9. Effective promotion of HPV vaccines, their purpose and impact on cervix cancer prevention and their availability in which healthcare centers can be done, especially in higher secondary schools.

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ANNEXURES

ANNEXURE – I: ETHICS APPROVAL LETTER

1) TNMGRMU IEC



THE TAMIL NADU DR. MGR, MEDICAL UNIVERSITY,
CHENNAI-600032
Institutional Ethics Committee

Proposal No: ECMGR0309186

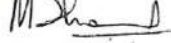
Date: 26.07.2021

CERTIFICATE

This is to certify that the project No. ECMGR0309186 entitled "Reasons for the delay in Diagnosis for common cancers (Breast and uterine cervix) among women in Tamil Nadu: A Qualitative Approach" submitted by DR PARAMESWARI SRIJAYANTH, DEPARTMENT OF EPIDEMIOLOGY has been approved by the Institutional Ethics Committee, at the meeting held on 15-07-2021, under the following terms and conditions.

- This approval is valid for three years or the duration of the project whichever is less from the date of the Certificate.
- All procedures to be used on participants are professionally acceptable and standardized.
- All adverse events during the course of study must be recorded and reported to the IEC within a period of seven days
- Any change in the study procedure/site/investigator should be informed to the IEC.
- A yearly progress report of the project has to be submitted to the IEC for review.

Dr. Saramma Mini Jacob
Member Secretary of Ethics Committee
Institutional Ethics Committee
The TN Dr. MGR Medical University
No. 69, Anna Salai, Guindy, Chennai-600032
The Tamil Nadu Dr MGR Medical University


(Dr. S. Mini Jacob)
Member Secretary
Institutional Ethics Committee
The Tamil Nadu Dr MGR Medical University

508290

2) Kilpauk Medical College (Government Royapettah Hospital) IEC

GOVT. KILPAUK MEDICAL COLLEGE, CHENNAI-10

Protocol ID. No. 624/2021 Meeting held on 07/10/2021

Reg.No. ECR/1385/Inst/TN/2020

CERTIFICATE OF APPROVAL

The Institutional Ethics Committee of Govt. Kilpauk Medical College, Chennai reviewed and discussed the application for "REASONS FOR THE DELAY IN DIAGNOSIS OF COMMON CANCERS (BREAST AND UTERINE CERVIX) AMONG WOMEN IN TAMIL NADU: A QUALITATIVE APPROACH" Submitted by Dr Parameswari Srijayanth MBBS., MSc., (Epi), Principal Investigator, Associate Professor, Department of Epidemiology, The Tamil Nadu Dr. MGR Medical University, Chennai – 600032.

Proposal is APPROVED.

The Institutional Ethics Committee expects to be informed about the progress of the study any Adverse Drug Reaction Occurring in the Course of the study any change in the protocol and patient information /informed consent and asks to be provided a copy of the final report.

A.S.
21/10/2021
For **DME (OSD)**

Director of Medical Education (OSD)
Govt. Kilpauk Medical College
Kilpauk, Chennai - 10.

624/2021
07/10/2021

3) Adyar Cancer Institute IEC

CANCER INSTITUTE (WIA)
(REGIONAL CANCER CENTRE)
INSTITUTIONAL ETHICS COMMITTEE- NABH ACCREDITED
NABH Accreditation No: EC-CT-2020-0141
Re-Registration No. ECR/235/Inst/TN/2013/RR-19



05.11.2021

Reference Number: IEC/2021/ Nov 03

To,

Dr. Parameswari.S

Associate Professor, Department of Epidemiology,

The Tamilnadu Dr. M.G.R Medical University

Guindy, Chennai – 600 032

Subject: Ethics Committee Approval Letter.

Reference: Study Proposal Titled "Reasons for the delay in diagnosis of common cancers (Breast & Cervix) among women in Tamil Nadu"

Dear Dr. Parameswari,

This is with reference to your application dated 01st Sep 2021 for review of the above referenced study proposal under expedited review category. The ethics committee members reviewed the following documents,

1. IEC Covering Letter dated 01.09.2021
2. Study Protocol with Annexures
3. The Tamil Nadu Dr. MGR medical University Institutional Ethics Committee Approval letter dated 26.07.2021
4. Patient Information sheet and Informed Consent Form English & Tamil
5. Responses from PI to IEC queries dated 02.11.2021

The following members of the Institutional Ethics Committee, Cancer Institute (WIA), Adyar, Chennai 600 020 reviewed the study proposal in detail under the **Expedited Review Category** (through circulation mode) as per Institutional Ethics Committee Standard Operating procedure.

Phone: 044-22209150 Extn: 135/219, Fax: 044-22354508
E-mail: iec@cancerinstitutewia.org

S. No	Name of Member	Role/ Designation in Ethics Committee	Affiliation of the Member with Institution	Reviewed On
1	Dr. J.S.Sathyannarayana Murthy	Chairman	Not affiliated with Cancer Institute	05.11.2021
2	Dr. R. Swaminathan	Member Secretary	Affiliated with Cancer Institute	01.11.2021
3	Dr. Lakshminarasimhan	Clinician	Not Affiliated with Cancer Institute	25.10.2021
4	Dr. C. Suthakaran	Medical Scientist	Not Affiliated with Cancer Institute	26.10.2021
5	Dr. J. C. Bose	Clinician	Not Affiliated with Cancer Institute	26.10.2021
6	Dr. B. Ananthi	Clinician	Affiliated with Cancer Institute	26.10.2021
7	Mrs. Sudha Ganapathy	Social Scientist	Not Affiliated with Cancer Institute	26.10.2021

Dr. R. Swaminathan did not participate in the decision making.

The study proposal and the submitted documents were reviewed and approved by the Ethics Committee to be conducted in its presented form.

The Institutional Ethics Committee, Cancer Institute (WIA) functions in accordance with:

The New Drugs and Clinical Trials Rules 2019, Good Clinical Practice Guidelines for Clinical Trials in India issued by CDSCO and Ministry of Health and Family Welfare, Government of India, National Ethical Guidelines for Bio-Medical and Health Research involving Human Participants issued by ICMR and ICH-GCP Guidelines.

The ethics committee expects to be informed about the progress of the study. Please note that it is the responsibility of the Principal Investigator to inform the IEC regarding any SAE occurring in the course of the study, or any changes in the protocol and patient information sheet /informed consent form, if applicable. You are also requested to provide a copy of final report to IEC.

Yours Sincerely,


Dr. J. S. Sathyannarayana Murthy

Chairman- IEC



4) DMS Approval Letter – For Stakeholders Interview

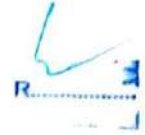
OP: 15

MEDICAL AND RURAL HEALTH SERVICES DEPARTMENT

From
Dr.S.Gurunathan ,MS.(G.S.),
Director of Medical and Rural Health Services,
Chennai 600 006.

EMR

41138



To
The Registrar
Tamil Nadu Dr.MGR.Medical University,
No.69,Anna salai,
Guindy,
Chennai-32.

Sir,

Ref. No.64064/P&D III/3/21, dt.20.11.2021

Sub: P&D- Department of Epidemiology-The Tamil Nadu Dr.MGR Medical University -Seeks Permission to conduct In-depth interview among stakeholders, Key Persons who are employed at Government Health care services for the approved project entitled,'Reasons for delay in diagnosis of common cancers (Breast and Uterine Cervix) among women in Tamil Nadu: A Mixed Method' under the Operational Research Programme- Tamil Nadu Health System Reform Programme- Permission - Reg.

Ref: Lr.Dated:13.10.2021 of the Registrar,The Tamil nadu Dr.M.G.R Medical University,Chennai-32.

As requested in your letter cited, permission is hereby granted to conduct interview among the stakeholders, key persons employed at Government Hospitals under this Directorate control, to explore and assess the reasons for the delay and acceptance among women to undergo screening for breast cervix cancers, and it is requested to carry out the interview with out any adverse events during the duration of the interview and to maintain confidentiality regarding the data gathered from the participants and not to share the same with anyone outside the research team.

Yours Faithfully



For Director of Medical and Rural
Health Services

11/20/21
22/11/21

ANNEXURE II – BILINGUAL INFORMED CONSENT FORM (English & Tamil)

Informed consent form

தமிழ்நாடு டாக்டர் எம்.ஜி.ஆர். மருத்துவப் பல்கலைக்கழகம்
The Tamil Nadu Dr.M.G.R. Medical University

Informed Consent Form for participating in the research study

Dr Parameswari Srijayanth MBBS., MSc., (Epi)
Principal Investigator
Associate Professor
Department of Epidemiology
The Tamil Nadu Dr. MGR Medical University

Project Name: Reasons for the delay in diagnosis of common cancers (Breast and Uterine Cervix) among women in Tamil Nadu: A mixed method approach

Part I: Information Sheet

Introduction

I am Dr Parameswari Srijayanth, MBBS., MSc., Associate professor in the Department of Epidemiology, of The Tamil Nadu Dr MGR medical university. I am doing research on the “**Reasons for the delay in diagnosis of common cancers (Breast and Uterine Cervix) among women in Tamil Nadu: A mixed method approach**”. The research participants will include cancer patients, healthy women and stakeholders.

Purpose of the research

This study aims to enumerate the reasons for delay in the screening of Common Cancers in Women, despite the screening services available at the Government Hospitals and Primary Health Centre.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate in all the services you receive at this Centre will continue and nothing will change.

Procedures

You will be participating in an interview with the interviewer. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. Information recorded is confidential, and no one else except me will access the information documented during your interview.

Duration

The research will take place over about a month in total. During that time, each interview will last for about 20 minutes each.

Risks

We are asking you to share with us some very personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview. There is absolutely no risk for you to take part in this study.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more to the scientific world.

Confidentiality

We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name.

Sharing the Results

The knowledge that we get from this research will be shared with you and your community before it is made widely available to the public. Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your job or job-related evaluations in any way. You may stop participating in the interview at any time that you wish without your job being affected.

This proposal has been reviewed and approved by the Ethics Review Committee of the TNMGRMU, which is supporting the study.

Part II: Certificate of Consent (This section is mandatory)

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of Participant _____

Signature of Participant _____ Date _____

Day/month/year

If illiterate,

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Thumb print of participant

Signature of witness _____

Date _____

Day/month/year

தமிழ்நாடு டாக்டர் எம்.ஜி. ஆர். மருத்துவப்பல்கலைக்கழகம்
கொள்ளை நோயியல் துறை
தகவல் ஒப்புதல் படிவம் பங்கேற்கும் ஆய்வு

டாக்டர் பரமேஸ்வரி ஸ்ரீஜயந்த் MBBS., MSc., (EPI)
முதன்மை ஆய்வாளர்
இணை பேராசிரியர்
நோய்தொற்றியல் துறை
தமிழ்நாடு டாக்டர் எம்.ஜி. ஆர் மருத்துவ பல்கலைக்கழகம்

வணக்கம்!

திட்டத்தின் பெயர்: தமிழ்நாட்டில் பெண்கள் மத்தியில் காணப்படும் பொதுவான புற்றுநோய்கள் (மார்பக மற்றும் கருப்பை கருப்பை வாய் புற்றுநோய்கள்) கண்டறிவதில் தாமதம் ஏற்படுவதற்கான காரணங்கள்: கலப்பு முறை ஆய்வு

பகுதி I: தகவல் தாள்

முகவுரை

டாக்டர் பரமேஸ்வரி ஸ்ரீஜயந்த், எம்.பி.பி.எஸ்., எம்.எஸ்.சி., ஆகிய நான் தமிழ்நாடு டாக்டர் எம்.ஜி.ஆர் மருத்துவ பல்கலைக்கழகத்தின் ஆகிய நான் நோய்தொற்றியல் துறையின் இணை பேராசிரியர். "தமிழ்நாட்டில் பெண்களிடையே காணப்படும் பொதுவான புற்றுநோய்கள் (மார்பக மற்றும் கருப்பை கருப்பை வாய் புற்றுநோய்கள்) கண்டறியப்படுவதில் தாமதத்திற்கான காரணங்கள்" குறித்து நான் ஆராய்ச்சி செய்கிறேன். இந்த ஆய்வில் பின்வரும் மக்கள் பங்குப்பெறுகிறார்கள் : மார்பக மற்றும் கருப்பை வாய் புற்றுநோயால் பாதிக்கப்பட்ட நோயாளிகள், 18-60 வயதிற்குட்பட்ட ஆரோக்கியமான பெண்மணிகள், இவர்கள் இருவரது நலனில் அக்கறைக்கொண்ட அரசு மற்றும் அரசு சாரா அதிகாரிகள் மற்றும் பங்குதாரர்கள்.

ஆராய்ச்சியின் நோக்கம்

அரசு மருத்துவமனைகள் மற்றும் ஆரம்ப சுகாதார மையத்தில் பரிசோதனை சேவைகள் கிடைத்தாலும், பெண்களுக்கு பொதுவான புற்றுநோய்கள் பரிசோதிக்கப்படுவதில் தாமதத்திற்கான காரணங்களை விவரிப்பதை இந்த ஆய்வு நோக்கமாகக் கொண்டுள்ளது.

ஆய்வின் நோக்கம்:

இந்த ஆய்வு மேலே கூறியவர்களின் நோய் தாக்கத்தின் நோயியல் முறைமையை கண்டறியப்படுவதில் தாமதத்திற்கான காரணங்கள் குறித்து அறியும் முயற்சி

தன்னார்வ பங்களிப்பு:

இந்த ஆராய்ச்சியில் உங்களது பங்களிப்பு தன்னார்வமானதே. இதில் பங்கேற்பதும் பங்கேற்காமல் இருப்பதும் உங்கள்விருப்பம். இதில் நீங்கள் பங்கேற்காமல் போனாலும் உங்கள் நோய்க்கான சிகிச்சையை இந்த மையத்தில் நீங்கள் பெறுவதில் எந்தமாற்றமும் இருக்காது.

செயல்முறை:

ஒரு நேர்காணலில் நீங்கள் பங்கேற்பீர்கள். நேர்காணலின் போது எந்தவொரு கேள்விக்கும் நீங்கள் பதிலளிக்க விரும்பவில்லை என்றால், நீங்கள் பதிலளிக்க விரும்பவில்லை என்று கூறலாம். மேலும் நேர்காணல் செய்பவர் அடுத்த கேள்விக்குச் செல்வார். பதிவுசெய்யப்பட்ட தகவல்கள் ரகசியமானது, உங்கள் நேர்காணலின் போது ஆவணப்படுத்தப்பட்ட தகவல்களை என்னைத் தவிர வேறு யாரும் அணுக மாட்டார்கள். மருத்துவ வாய்வழி பரிசோதனையைத் தொடர்ந்து நேர்காணலில் பங்கேற்பாளர்கள் பங்கேற்க வேண்டும்.

காலஅவகாசம்:

இந்த ஆராய்ச்சி சுமார் ஒரு மாத காலம் நடைபெறும். அதில் ஒவ்வொரு நேர்காணலும் சுமார் இருவது நிமிடங்கள் நடக்கும்.

அபாயநேர்வு:

மிகவும் தனிப்பட்ட மற்றும் ரகசியமான சில தகவல்களை எங்களுடன் பகிர்ந்து கொள்ளுமாறு நாங்கள் உங்களிடம் கேட்டுக்கொள்கிறோம். மேலும் சில தலைப்புகளைப் பற்றி பேசுவதில் உங்களுக்கு சங்கடமாக இருக்கலாம். நீங்கள் அவ்வாறு செய்ய விரும்பவில்லை என்றால் நீங்கள் எந்த கேள்விக்கும் பதிலளிக்க வேண்டியதில்லை அல்லது நேர்காணலில் பங்கேற்க வேண்டியதில்லை. அதுவும் நல்லது. எந்தவொரு கேள்விக்கும் பதிலளிக்காததற்கு அல்லது நேர்காணலில் பங்கேற்க மறுத்ததற்கு நீங்கள் எங்களுக்கு எந்த காரணத்தையும் கூற வேண்டியதில்லை. இந்த ஆய்வில் நீங்கள் பங்கேற்க எந்த ஆபத்தும் இல்லை.

நன்மைகள்:

உங்களுக்கு நேரடி நன்மை எதுவும் இருக்காது. ஆனால் அறிவியல் உலகிற்கான ஒரு பெரும் உதவி ரகசியத்தன்மை:

நீங்கள் பகிரும் எந்த ஒரு தகவலும் எங்கள் ஆராய்ச்சி குழுமத்தை தவிர வெளியில் பகிரப்படாமல் அந்தரங்கமாக வைக்கப்படும். நீங்கள் அளிக்கும் தகவலிலும் உங்கள் பெயருக்கு பதில் உங்களுக்கான ஒரு எண் மட்டுமே போடப்படும்.

பயன்முடிவு:

இந்த ஆராய்ச்சியிலிருந்து நாங்கள் பெறும் அறிவு பொதுமக்களுக்கு பரவலாக கிடைக்குமுன் உங்களுக்கும் உங்கள் சமூகத்துக்கும் பகிரப்படும். இன்று நீங்கள் எங்களிடம் கூறும் எதுவும் ஆராய்ச்சி குழுவுக்கு வெளியே உள்ள யாருடனும் பகிரப்படாது. மேலும் பெயரால் எதுவும் உங்களுக்குக் கூறப்படாது.

நிராகரிக்க அல்லது பின்வாங்கும் உரிமை:

நீங்கள் அவ்வாறு செய்ய விரும்பவில்லை என்றால் இந்த ஆராய்ச்சியில் நீங்கள் பங்கேற்க வேண்டிய அவசியமில்லை, மேலும் பங்கேற்கத் தேர்ந்தெடுப்பது உங்கள் வேலை அல்லது வேலை தொடர்பான மதிப்பீடுகளை எந்த வகையிலும் பாதிக்காது. உங்கள் வேலை பாதிக்கப்படாமல் நீங்கள் விரும்பும் எந்த நேரத்திலும் நேர்காணலில் பங்கேற்பதை நிறுத்தலாம். இந்த முன்மொழிதல் தமிழ்நாடு டாக்டர் எம்ஜிஆர் பல்கலைக்கழகத்தின் நீதிநெறி ஆய்வுகுழுவால் மதிப்பாய்வு செய்யப்பட்டு ஒப்புதல் அளிக்கப்பட்டது.

பகுதிஇரண்டு :

ஒப்புதல்சான்றிதழ் (இந்தபகுதிகட்டாயமாகும்)

மேற்கூறிய முன்னேற்பாடான தகவல்கள் அனைத்தும் தெளிவாகபடித்துவிட்டேன். அல்லது எனக்கு படித்துக்காட்டப்பட்டது. அதை சார்ந்த சந்தேகங்களை கேட்கும்வாய்ப்பு எனக்கு அளிக்கப்பட்டதோடு என்கேள்விகளுக்கும் மனநிறைவு பெரும்வகையில் பதில்கள் அளிக்கப்பட்டது. இந்த ஆராய்ச்சியில் பங்குபெற முழுமனதுடன் தன்னார்வமாக ஒப்புதல்அளிக்கிறேன்.

பங்கேற்பாளரின்பெயர்:

பங்கேற்பாளரின்கையெழுத்து:

தேதி:

(நாள்/மாதம்/வருடம்)

படிப்பறிவு இல்லாதவராயின்,

இந்தஒப்புதல் படிவத்தின் துல்லியமான தகவல்களை சாத்தியமான பங்கேற்பாளரிடம் படித்துக்காட்டியதை கண்டறிந்தேன். அந்த பங்கேற்பாளருக்கு கேள்வி மற்றும் சந்தேகங்களை கேட்கும் வாய்ப்பும்வழங்கப்பட்டது. இந்த ஆராய்ச்சியில் அவர்பங்கேற்பதற்கான முழு ஒப்புதலையும் நான் உறுதிசெய்கிறேன்.

சான்றுஅளித்தநபரின் பெயர்:

சான்றுஅளித்தநபரின் கையொப்பம்:

பங்கேற்பாளரின் இடது பெருவிரல் அச்சு:

தேதி:

(நாள்/மாதம்/வருடம்):



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8.	Occupation (of both Self & Head of the family) தொழில் (பங்கேற்பவர் (ம) குடும்ப தலைவர்)	: <input type="checkbox"/> Self <input type="checkbox"/> Spouse	1.Legislators, Senior Officials & Managers. 2.Professionals 3.Technicians and Associate Professionals 4.Clerks 5.Skilled Workers and Shop & Market Sales Workers 6.Skilled Agricultural & Fishery Workers 7.Craft & Related Trade Workers 8. Plant & Machine Operators and Assemblers 9. Elementary Occupation 10.Unemployed
9.	Literacy (of both Self & Head of the family) (பங்கேற்பவர் (ம) குடும்ப தலைவர்)	: <input type="checkbox"/> Self <input type="checkbox"/> Spouse	1.Profession or Honours 2.Graduate 3.Higher secondary or Intermediate or Diploma 4.High school 5.Middle School 6.Primary School
10.	Monthly income	: <input type="checkbox"/> Self <input type="checkbox"/> Spouse	1. ≥123,322 2. 61,663-123,321 3. 46,129-61,662 4. 30,831-46,128 5. 18,497-30,830 6. 6,175-18,496 7. ≤ 6174
Sec II: History			
11.	Marital Status	<input type="checkbox"/>	1.Married 2.Unmarried 3.Separated 4.Divorced 5.Deserted 5.Remarried
12.	If Husband	<input type="checkbox"/>	1.Alive 2.Dead 3.Dont Know



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13.	Status of Husband's Health (ask for HIV) கணவரின் உடல் நிலை	<input type="checkbox"/> 1.Healthy <input type="checkbox"/> 2.Sick <input type="checkbox"/> 3.Dont know
14.	Had Consanguineous Marriage? உறவுமுறைக்குள் திருமணம் புரிந்தவரா?	: <input type="checkbox"/> 1.Yes; 2. No
15.	If Yes, Choose the category	: <input type="checkbox"/> 1. Married to Parent, Child, Sibling <input type="checkbox"/> 2. Married to aunt, Uncle, niece, Nephew, Grandparent, Grand Children <input type="checkbox"/> 3. Married to First Cousin
Children (குழந்தைகள் பற்றிய விவரம்)		
16.	Whether have children/ குழந்தைகள் உள்ளனரா?	: <input type="checkbox"/> 1. Yes (Parous) <input type="checkbox"/> 2. No (Nulliparous)
17.	Number of Children குழந்தைகளின் எண்ணிக்கை	: <input type="checkbox"/> Alive <input type="checkbox"/> Dead
18.	Reasons for Death, Specify	: _____
19.	Age at Death	: <input type="text"/> <input type="text"/> Years <input type="text"/> <input type="text"/> Months
20.	Details of child birth (Write 9- Don't Know&99 - NA)	1 st 2 nd 3 rd 4 th 5 th 6 th 7 th
20.1	Type of delivery (பிரசவ முறை) (1-Normal;2-LSCS;3-Forceps;4-Vacuum)	
20.2	Outcome (பிரசவத்தின் போது குழந்தையின் நிலை/ ஆரோக்கியம்) (1- Live birth;2- still birth;3-Abortion)	
20.3	Gender of Child (குழந்தை- ஆணா/பெண்ணா) (1-Male;2-Female)	
20.4	Mother's age at the time of delivery (in years) பிரசவத்தின் போது தாயின் வயது	
20.5	Whether Breast fed? (1-Yes; 0-No) தாய்ப்பால் புகட்டப்பட்டதா?	
20.6	If yes, Duration in months எத்தனை மாதம் வரைத் தாய்ப்பால் புகட்டப்பட்டது	
20.7	If no, why? தாய்ப்பால் புகட்டப்படவில்லையெனில் காரணம்?	
20.8	Exclusively Breastfed (1-Yes; 0-No) தாய்ப்பால் மட்டும் தரப்பட்டதா?	



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20.9	If yes, till what age? (in months) ஆமெனில் எந்த வயது வரை								
20.10	Age of weaning (in months) பால் மறப்பித்தல் ஏற்பட்ட வயது.								
20.11	Child's present Status (1-Healthy 2-Others) தற்பொது குழந்தையின் ஆரோக்கிய நிலை								
Medical History									
21.	Any underlying medical conditions present? உடலில் ஏதேனும் மருத்துவக் குறைப்பாடு உள்ளனவா?	:	<input type="checkbox"/>	1.Diabetes mellitus; 2. Hypertension; 3. COPD; 4.Cardio vascular disease; 5.Hepatitis B; 6.Renal-diseases; 7.Cerebro-vascular diseases; 8.Obesity; 9. Seizure disorders; 10. thyroid disorders; 11. STDs; 12. Tuberculosis; 13. HIV; 15 Others 16. None					
22.	If others, Specify (மற்றவையெனில் விவரிக்க)	:							
Surgical History									
23.	History of Previous surgeries முன்பெதேனும் அறுவை சிகிச்சை செய்யப்பட்டதா?	:	<input type="checkbox"/>	1.Yes; 2. No					
24.	If yes, specify (Check records if available) ஆம் எனில் விவரிக்க	:							
Hospitalisation History									
25.	History of previous Hospitalisation இதற்கு முன்பு எப்பொதேனும் மருத்துவமனையில் அனுமதிக்கப்பெற்றீரா?	:	<input type="checkbox"/>	1.Yes; 2. No					
26.	If yes, specify ஆம் எனில் விவரிக்க	:							
Cancer History									
27.	History of cancers (Exclude Breast & Cervix: CA) வேறு ஏதேனும் புற்று நோய் தாக்கம் ஏற்பட்டதா?	:	<input type="checkbox"/>	1.Yes; 2. No					
28.	If yes, Describe. ஆம் எனில் விவரிக்க	:							
Family Cancer History									
29.	Has anyone diagnosed with any form of cancer in your paternal or maternal lineages? தாய் (அ) தந்தை வழியில் யாரேனும் புற்றுநோயால் பாதிக்கப் பெற்றனரா?	:	<input type="checkbox"/>	1.Yes; 2. No					



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30.	If yes, Specify Who? Relationship : _____ ஆம் எனில் பாதிக்கப்பெற்றவர் யார் ? அவருடன் உங்களது உறவுமுறை விவரிக்க	
31.	What type of cancer? புற்றின் வகை : _____	
32.	History of cancers in siblings : <input type="checkbox"/> 1.Yes; 2. No உடன் பிறந்தோர் யாரேனும் புற்றுநோயால் பாதிக்கப் பெற்றனரா?	
33.	If yes, Who? (Specify Relationship) : _____ ஆம் எனில் பாதிக்கப்பெற்றவர் யார் ? அவருடன் உங்களது உறவுமுறை விவரிக்க	
34.	What type of cancer? புற்றின் வகை : _____	
35.	History of cancers in children : <input type="checkbox"/> 1.Yes; 2. No உங்கள் குழந்தைகள் யாரேனும் புற்றுநோயால் பாதிக்கப் பெற்றனரா?	
36.	If yes, Who? (Specify Relationship) : _____ ஆம் எனில் பாதிக்கப்பெற்றவர் யார் ? அவருடன் உங்களது உறவுமுறையை விவரிக்க	
37.	What type of cancer? புற்றின் வகை : _____	
38.	Whether your parents had consanguineous marriage : <input type="checkbox"/> 1.Yes; 2. No உங்களது பெற்றோர் உறவுமுறைக்குள் மணமுடித்தனரா?	
39.	If Yes, Choose the category : <input type="checkbox"/> 1.Married to Parent, Child, Sibling 2.Married to aunt, Uncle, niece, Nephew, Grandparent, Grand Children 3.Married to First Cousin	
Usage of Contraceptive pills - Birth control / Infertility treatment/ HRT		
40.	Whether used any pills/tablets? : <input type="checkbox"/> 1.Yes; 2. No கருத்தடை மாத்திரைகள்/ ஹார்மோன் மாத்திரைகள் / குழந்தையின்மைக்கான சிகிச்சை மேற்கொண்டீரா? If yes, Describe, ஆமெனில் விவரிக்க : _____	



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41.	Used any physical barriers of contraception. கருத்தடை சாதனங்கள், பயன்படுத்தியுள்ளீரா?	: <input type="checkbox"/> 1.Yes; 2. No
42.	If yes, describe, ஆம் எனில் விவரிக்க பயன்படுத்தியது என்ன?	: <input type="checkbox"/> 1. Condoms 2. Copper -T 3. Loupe
Menstrual History		
43.	Attained Menarche? பருவமெய்தியவரா?	: <input type="checkbox"/> 1.Yes; 2. No
44.	Age at which attained menarche பருவமெய்திய வயது	: <input type="text"/> <input type="text"/> Years
45.	Any cycle irregularities? மாதவிடாய் சுழற்சியில் சிக்கல்கள் இருந்ததா?	: <input type="checkbox"/> 1.Yes; 2. No
46.	PCOS	: <input type="checkbox"/> 1.Yes; 2. No
47.	Attained Menopause மெனொபாஸ் எய்தியவரா?	: <input type="checkbox"/> 1.Yes; 2. No
48.	Age at which attained menopause மெனொபாஸ் எய்திய வயது.	: <input type="text"/> <input type="text"/> Years
49.	Record significant details, if any in menstrual history	: _____
50.	Abortions/ MTP done கருக்கலைப்பு செய்துள்ளீரா	: <input type="checkbox"/> 1.Yes; 2. No
51.	PI Specify / விவரிக்க	:
Personal Habits		
52.	Smoking Habits புகைப்பழக்கம் உண்டா?	: <input type="checkbox"/> Self <input type="checkbox"/> Spouse (1-Former; 2-Current; 3-Passive smoking; 0-None)



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53.	Duration of Smoking habit (in years) புகைப்பழக்கத்தின் கால அளவு	:	<input type="text"/> Self	<input type="text"/> Spouse
54.	Smokeless tobacco (Chewable/sniff) புகையில்லா புகையிலை பழக்கம் பான்/குட்கா/புகையிலை/பொடி	:	<input type="text"/> Self	<input type="text"/> Spouse 1-Former; 2-Current; 3-Passive smoking; 0-None
55.	Duration of this habit பழக்கத்தின் கால அளவு	:	<input type="text"/> Self	<input type="text"/> Spouse
56.	Alcoholism / குடிப்பழக்கம்	:	<input type="text"/> Self	<input type="text"/> Spouse 1-Former; 2-Current; 3-Passive smoking; 0-None
57.	Duration of alcoholism (in years) குடிப்பழக்கத்தின் கால அளவு	:	<input type="text"/> Self	<input type="text"/> Spouse
Circumcision				
58.	Husband (Male Circumcision)	:	<input type="text"/> 1.Yes; 2. No	
59.	Female Genital Mutilation	:	<input type="text"/> 1.Yes; 2. No	
Sexual History				
60.	Age at first Coitus முதன் முதலில் உடலுறவு கொண்ட வயது	:	<input type="text"/> <input type="text"/> Years	
61.	How is your sexual life? தாம்பத்ய உறவு எப்படி உள்ளது (கணவன் / மனைவி உறவு)	:	<input type="text"/> 1.Good 2. Fair 3. Bad	
62.	Frequency of Coitus தாம்பத்ய உறவின் அளவு	:	<input type="text"/> 1.Daily 2- more than twice in a week 3-once in a week 4-twice in a month 5-once in a month	
63.	Commercial Sex worker	:	<input type="text"/> 1.Yes;2.No	



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63.	Sexual Promiscuity (வெளித் தொடர்பு)	<input type="checkbox"/>	1.Yes; 2. Before 3.Not anymore 4.Never
64.	Are you sexually active? உங்களது தாம்பத்ய உறவு எப்படி உள்ளது.	<input type="checkbox"/>	1.Yes; 2. Before 3.Not anymore
65.	Nature of Sex	<input type="checkbox"/>	1.Protected; 2. Unprotected
66.	Usage of Condom காண்டம் உபயோகிப்பவரா?	<input type="checkbox"/>	1.Yes; 2. No
67.	If yes, Frequency of condom usage காண்டம் எப்போதெல்லாம் உபயோகிப்பீர்	<input type="checkbox"/>	1.Always 2-Infrequently 3-rarely 4.Never
Sec- III. KAP towards Health / Health seeking behavior (General)			
68.	In general, how much importance do you give for your health problem? பொதுவாக உடல் நலத்திற்கு எவ்வளவு முக்கியத்துவம் தருவீர்கள்.	<input type="checkbox"/>	1.Not Important 2.Fairly important 3.Very important
69.	In case, if you are sick, whom do you prefer to Consult for any health problems உடல் நலன் சுகமில்லாமல் போனால் ஆலோசனைக்கு யாரை அணுகுவீர்.	<input type="checkbox"/>	1.Allopath 2.AYUSH Physician 3.Health Nurse 4.Traditional Healers 5.Self-medication (Pharmacy) 6.Others
70.	Where do you prefer to go for consultation? உடல் நலன் சுகமில்லாமல் போனால் ஆலோசனைக்கு எங்கே செல்வீர்?	<input type="checkbox"/>	1. Self-medication - Pharmacy 2.Govt. health care facility 3.Private health care facility 4. Others
71.	Have you heard for full body check-up/Master Health check-up? முழு உடல் பரிசோதனை குறித்து கேள்விப்பட்டுள்ளீரா?	<input type="checkbox"/>	1.Yes 2.No



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72.	Have you undergone any master checkup? முழு உடல் பரிசோதனை மேற்கொண்டுள்ளீரா?	: <input type="checkbox"/> 1.Yes 2.No
73.	If yes, where was it done? ஆமெனில் எங்கே செய்தீர்?	: <input type="checkbox"/>
74.	How was it funded? அதற்கான செலவு யாருடையது?	: <input type="checkbox"/> 1.Self-funded 2.Sponsored (Company, insurance)
75.	Are you part of any ESI/CGHS/ECHS/scheme? ESI/CGHS/ECHS வசதி உள்ளதா?	: <input type="checkbox"/> 1.Yes 2.No
76.	Do you have Chief minister's Health card / PMJAY card? முதலமைச்சர் / பிரதமர் மருத்துவக் காப்பீட்டு திட்டம் உள்ளதா?	: <input type="checkbox"/> 1.Yes 2.No 3.Applied
77.	Do you have any private health insurance? வேறு ஏதேனும் தனியார் காப்பீட்டு திட்டம் உள்ளதா?	: <input type="checkbox"/> 1.Yes 2.No
Sec IV. Access to Health Care facility		
78.	Is there any nearest Government hospital / PHCs Setup near your residence? வீட்டினருகே ஏதேனும் அரசு மருத்துவமனை (ம) அரசு ஆரம்ப சுகாதார மையம் உள்ளதா?	: <input type="checkbox"/> 1.Yes 2.No
79.	Distance from your residence (in Kms) அதன் தூரம்	: <input type="checkbox"/>
80.	What about the transport facility to reach the Health Care facility அவைகளை சென்றடைய வாகன வசதி	: <input type="checkbox"/> 1.Adequate 2.Inadequate
81.	Type of transport வாகன வகை	: <input type="checkbox"/> 1.Govt. transport 2.Private transport 3.Own vehicle arrangement



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82.	What would be the approx. expenses incurred to reach the HCF? (Ask for one way expense) மருத்துவமனை சென்றடைய ஆகும் தோராய செலவு.	: <input type="text"/> in INR
83.	Do you have any VHNs /ANM visiting your Residence/locality கிராமப்புற சுகாதார செவிலியர் உங்கள் வீட்டருகே பணியமர்த்தப்பட்டுள்ளாரா?	: <input type="checkbox"/> 1.Yes 2.No
84.	Do you have their Contact number? அவரைத் தொடர்புக்கொள்ள தொலைப்பேசி எண் உள்ளதா?	: <input type="checkbox"/> 1.Yes 2. No
85.	Ask and record contact number.	: <input type="text"/>
Sec V. Knowledge about Cancer		
86.	Were you aware of cancer? பற்றுநோயை பற்றி அறிவீர்களா?	: <input type="checkbox"/> 1.Yes 2.No
87.	List few Cancers you Know தெரிந்த பற்றுநோய்களை கூறுங்கள்	:
88.	Have you seen/ heard/read messages about Cancer பற்றுநோயைக் குறித்து தகவல்கள் படித்து, கேட்டுள்ளீர்களா?	: <input type="checkbox"/> 1.Yes 2.No
89.	If yes, describe, where ஆமெனில் எங்கே?	: <input type="text"/>
90.	Can Cancer be prevented? பற்றுநோயைத் தடுக்க முடியுமா	: <input type="checkbox"/> 1.Yes 2.No
100.	Can Cancer be Cured? பற்றுநோயை குணப்படுத்த முடியுமா	: <input type="checkbox"/> 1.Yes 2.No



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101	Should patients treated of Cancer be kept on Regular follow-up குணமடைந்த நோயாளிகள் தொடர் கண்காணிப்பில் வைக்கப்படுதல்	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
Sec VI. Knowledge about Cancer Screening		
102.	Have you seen/heard/read messages about cancer screening? புற்றுநோயைக் கண்டறியும் முறைகளைக் கேள்விப்பட்டுள்ளீரா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
104.	Is cancer screening available at your nearby Govt HCF? உங்கள் வீட்டின் அருகில் உள்ள அரசு சுகாதார மையங்களில் புற்றுக்கான பரிசோதனை செய்யும் வசதி உண்டா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No <input type="checkbox"/> 3.Don't know
105.	Were you aware of any screening activity/ campaign conducted at your locality புற்றுநோய் கண்டறியும் முகாம்கள் ஏதேனும் உங்கள் பகுதியில் எப்பொழுதாவது நடந்ததா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No <input type="checkbox"/> 3.Don't know
If Yes, ask Q.No 106 to 107		
106.	Where / எங்கே When / எப்போது Frequency, if any / எத்தனை முறை	
107.	Have you ever attended any such screening camps? இது போன்ற புற்றுநோய் முகாம்களில் பங்கேற்றுள்ளீரா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
108.	If No, why dint you attend? இல்லையெனில் ஏன் பங்கேற்கவில்லை	<input type="checkbox"/> 1.Lots of male around; 2.Shy/Embarassment 3.Fear; 4.unnecessary;5.Not required 6.Waste of time; 7.Others; 8.Don't Know



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109.	Who was the organisers of such campaign? இது போன்ற புற்றுநோய் முகாம்களை யார் நடத்தினார்கள்?	: <input type="checkbox"/> Govt <input type="checkbox"/> NGO <input type="checkbox"/> Private Hospital
110.	Was any Screening done in such Camps? புற்றுநோயைக் கண்டறியும் பரிசோதனை செய்தனரா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
111.	If yes, what are the Screening tests done, there? Pl list ஆமெனில், எந்த பரிசோதனை முகாம்களில் செய்யப்பட்டன	:
112.	Do you know about Noncommunicable diseases clinics	: <input type="checkbox"/> 1.Yes;2.No
113.	Have you done any screening for NCDs NCD பரிசோதனை மேற்கொண்டீர்களா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
114.	List all NCD disease screened there, Pl	: _____
115.	Who told you / motivated you to do NCD/Cancer screening யாரால்/எதனால் பரிசோதனை மேற்கொண்டீர்கள்?	<input type="checkbox"/> 1.Self <input type="checkbox"/> 2.Family/Friends/Colleagues <input type="checkbox"/> 3.Ad/Hoarding/Government Camp/Pamphlets <input type="checkbox"/> 4.Our VHN <input type="checkbox"/> 5.Family Physician <input type="checkbox"/> 6. suspicion of anysymptom <input type="checkbox"/> 7. Any Disease /illness
Sec 6. KAP about Breast and Cervical cancer Screening		
116.	Do you do self- examination of your breast in front of mirror? மார்பகங்களை சுயபரிசோதனை செய்வீர்களா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
117.	Have you ever done any screening test exclusively for Breast cancer மார்பக புற்றுநோய்க்கான ப்ரத்யேக பரிசோதனை செய்வீர்களா?	: <input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
118.	If yes, What tests among the lists. பின்வருவனவற்றுள் எவை	<input type="checkbox"/> 1.Breast Clinical Examination <input type="checkbox"/> 2.USG; 3. Mammogram <input type="checkbox"/> 4. X-ray; 5. CT; 6.MRI <input type="checkbox"/> 7. Tomogram 8.Others <input type="checkbox"/> 9.Dont Know



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119. What was the result of last Breast CA screening கடைசியாக செய்த மார்பக புற்று கண்டறியும் பரிசோதனை முடிவுகள் என்ன?	: <input type="checkbox"/> 1.Positive <input type="checkbox"/> 2.Negative <input type="checkbox"/> 3.Inconclusive, need further evaluation <input type="checkbox"/> 4.Not collected <input type="checkbox"/> 5.Missing <input type="checkbox"/> 6.Don't Know
120. How long it took to get Breast CA Screening test results? கடைசியாக செய்த மார்பக புற்று கண்டறியும் பரிசோதனை முடிவுகள் கிடைக்க எவ்வளவு நாட்கள் எடுத்தது	<input type="text"/>
121. Have you ever done any screening test exclusively for Cervical cancer முன்பு எப்பொழுதாவது கருப்பை வாய்புற்று - பரிசோதனை செய்தீரா?	<input type="checkbox"/> 1.Yes <input type="checkbox"/> 2.No
122. If Yes, what among the lists பின்வருவனவற்றுள் எவை Tick all boxes , that are applicable	: <input type="checkbox"/> Colposcopy <input type="checkbox"/> PAP smear <input type="checkbox"/> HPV testing <input type="checkbox"/> Via villi <input type="checkbox"/> Xray <input type="checkbox"/> CT <input type="checkbox"/> MRI <input type="checkbox"/> Others <input type="checkbox"/> Don't know
123. If screening not done for both Cancers, Why? மேலே கூறிய இவ்விரு புற்றுக்களுக்கும் பரிசோதனை செய்யவில்லை, எனில் என்னென்ன காரணங்கள் ? Tick all boxes , that are applicable	<input type="checkbox"/> Male doctor <input type="checkbox"/> Shy/Embarassment <input type="checkbox"/> Fear <input type="checkbox"/> unnecessary <input type="checkbox"/> Not required <input type="checkbox"/> Waste of time <input type="checkbox"/> Others <input type="checkbox"/> Don't Know



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124.	What was the result of last Cervical CA screening கடைசியாக செய்த கருப்பை வாய்ப்புற்று கண்டறியும் பரிசோதனை முடிவுகள் என்ன?	: <input type="checkbox"/>	1.Positive 2.Negative 3.Inconclusive, need further evaluation 4.Not collected 5.Missing 6.Don't Know
125.	How long it took to get Cervical CA Screening test results? கடைசியாக செய்த கருப்பை வாய்ப்புற்று கண்டறியும் பரிசோதனை முடிவுகள் கிடைக்க எவ்வளவு நாட்கள் எடுத்தது	: <input type="text"/>	
126.	List the symptoms of Breast CA (write don't know, if not known) மாற்பக புற்றுக்கான அறிகுறிகள்.	:	
127.	List the symptoms of Cervical CA (write don't know, if not known) கருப்பை வாய்புற்றுக்கான அறிகுறிகள்	:	
128.	What is the right age to start Regular Breast CA Screening? மாற்பக புற்றுக்கான பரிசோதனை எந்த வயதில் இருந்து ஆரம்பிக்க வேண்டும்	: <input type="text"/>	Years
129.	What is the right age to start Cervical CA Screening? கருப்பை வாய்புற்றுக்கான பரிசோதனை எந்த வயதில் இருந்து ஆரம்பிக்க வேண்டும்.	: <input type="text"/>	
130.	Has your VH/N/ANM done cancer Screening to you? கிரமப்புற சுகாதார செவிலியர்கள் புற்றுக்கான பரிசோதனை செய்தாரா?	: <input type="checkbox"/>	1.Yes 2.No



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Annexure I

Quantitative Tool
Common for all participants, Except Stakeholders

Participant ID:

131.	If yes, what tests she had done? ஆமெனில் என்னென்ன செய்தார்கள், list	:	<input type="checkbox"/> Write 9 if Don't Know Otherwise list out
132.	What was the result? பரிசோதனை முடிவு என்ன?	:	<input type="checkbox"/> 1.Positive 2.Negative 3.Inconclusive, need further evauation 4.Not collected 5.Missing 6.Don't Know
133.	Time taken for the result. பரிசோதனை முடிவு கிடைக்க எவ்வளவு நேரம் எடுத்தது.	:	
136.	If found positive, what was said பரிசோதனை முடிவு, Positive எனில் என்ன செய்ய அறிவுறுத்தப்பட்டது.	:	
137.	If found negative, what was said பரிசோதனை முடிவு, negative எனில் என்ன செய்ய அறிவுறுத்தப்பட்டது.	:	
138.	If found doubtful, what was said பரிசோதனை முடிவு, doubtful எனில் என்ன செய்ய அறிவுறுத்தப்பட்டது.	:	
139.	Did VHN/ANM helped in seeking further doctor's Consultation VHN/ANM மருத்துவரை அணுகி ஆலோசனை பெற உதவினரா?	:	
140.	Who will accompany you to Hospital/ Screening/Camps மருத்துவமனைக்கு துணையாக யார் வருவார்?	:	<input type="checkbox"/> 1. Husband 2.Parents/in-laws 3.Siblings 4.Relatives 5.Friends 6.None



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Annexure I

Quantitative Tool
Common for all participants, Except Stakeholders

Participant ID:

141.	Are you aware of HPV Vaccines?	:	<input type="checkbox"/>	1. Yes
	HPV தடுப்பூசிகள் பற்றி அறிவீர்களா?			2. No
142.	If Yes, describe / ஆமெனில் விவரிக்க	:		
143.	Where have you heard? எங்கே கேள்வி பட்டீர்கள்?	:		
144.	Why it is given? எதற்காக தருகிறோம்	:		
145.	Who is the ideal candidate, for HPV? இந்த தடுப்பூசி பெறுவதற்கு பொருத்தமானவர்கள் யார்?	:		
146.	Have you ever had HPV Vaccines? HPV தடுப்பூசி போட்டுள்ளீர்களா?	:		
147.	Details. விவரிக்க.	:		



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Annexure II

**Applicable for all participants diagnosed with CA Breast & CA Cervix
attending FGD and/ or IDI**

Participant ID:

Cross verify patient's response from records wherever possible

Disease nature and status	
1. Height	:
2. Weight	:
3. Diagnosis	: <input type="checkbox"/> 1- CA Breast 2- CA Cervix
4. Age at Diagnosis	: <input type="checkbox"/> Years
5. Cancer Staging	: <input type="checkbox"/> 0- Dysplasia & CIS 1- Stage I 2-Stage II 3-Stage III 4-Stage IV
6. Procedures Carried out (from Records)	:
7. Date: Noticed first Symptom	:
8. Time delay: Patient Delay / Health Care delay	:
9. Date of final diagnosis Screening Procedures with date	:
10. Diagnostic Procedures with date	:
11. Treatment Procedures with date	:
12. Current State	:



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Annexure III

Cancer patients: Breast & Cervix

FGD and/ or IDI interview guide

Participant ID:

Ser No	Questions	Strongly disagree	disagree	Neutral	Agree	Strongly agree
1.	I wish I knew more about cancer					
2.	I wish I knew more about cancer screening					
3.	The screening facilities at the HCF were adequate.					
4.	I feel guilty of acquiring cancer					
5.	My family / friends were supportive.					
6.	I am not comfortable sharing my diagnosis to others.					
7.	I was asked not to share my diagnosis to others by my husband/family member					
8.	I never felt the need to hide my diagnosis					
9.	I am unhappy with the people's attitude towards my diagnosis					
10.	I am happy with the cancer care I receive.					

2) Patient Interview Guide (For FGD & IDI)



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Cancer patients: Breast & Cervix

FGD and/ or IDI interview guide

Annexure III

Participant ID:

1. What do you know about the word cancer?
2. Where do you came to know about this word cancer?
3. What is your experience about cancer?
4. What do you think had caused cancer to you?
5. What was your first symptom?
6. Have you heard about cancer before your diagnosis? Describe that, please.
7. How do you think cancer can be prevented?
8. How many of you heard about cancer screening?
9. Share your experiences about cancer screening?
10. What was your initial symptoms? Share your experiences.
11. Pl share the events that followed since first noticing the symptoms
12. Symptoms to Diagnosis: Share your experiences how did you arrive at diagnosis.
13. Collect the time taken between first noticing symptom to diagnosis
14. Collect the time taken between diagnosis to starting treatment
15. Ask sensibly and record their reactions and responses, when they learnt about their diagnosis
16. Comment on your family, relatives' and friends' support.
17. What was their reactions?
18. Share us your experience with the hospital.
19. Share us your experience about the doctor.
20. Share us your experience about the treatment.
21. Describe your financial support?
 - a) For the treatment
 - b) For the daily livelihood
22. How was the employers support, in providing leave, financial assistance, moral support?
 - a) for the patient
 - b) for the breadwinner
23. Tell us, how do you feel, if you can completely beat cancer and be cured.
24. Tell us, what all the things that need to be improved on cancer care.

3) Non-Cancer participant interview guide (For FGD & IDI)



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Healthy Controls: FGD and/ or IDI

Annexure IV

Participant ID:

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1. What do you know about the word cancer?
2. Where do you came to know about this word cancer?
3. Any personal experience about cancer? (நுண்பர்கள், உறவினர்கள் யாரேனும் பாதிக்கப்பட்டுள்ளீரா?)
4. How do you think cancer can be prevented?
5. Have you heard about cancer screening? What is your opinion about Cancer Screening?
6. Share your experiences about cancer screening?
7. Who are all should undergo Cancer screening?
8. Comment on your family, relatives' and friends' support, if you intend to undergo Screening.
9. What would be their reactions, if you disclose to undergo cancer screening?
10. List Common Cancers among Women.
11. When do you think, a woman should start undergo screening for women?
12. Do you have any experience, undergoing screening at the hospital? Share with us.
13. Share from your experience about the health care facility, where you undergone Screening.
14. In the absence of symptoms, how do you think people be motivated for cancer screening.
15. Tell us, how do you feel, if one can completely beat cancer and get cured.
16. Tell us, what all the things that need to be improved on cancer care.

4) Stakeholder Interview Guide (For IDI)

Annexure VI

Stakeholders – Interview Guide

Name

Age

Qualification

Designation

Years of experience

1. Describe things to improve screening for breast and CA uterine cervix
2. Are patients aware of the screening
3. Are patients aware of cancer
4. What are the lacunae in the existing system of health care?
5. Is manpower sufficient to conduct screening, counsel patients?
6. What are the barriers to women accessing health care facility?
7. What are the facilitators in accessing health care facility?
8. Whom do you blame for the delay? (patient, public health care, private health care, traditional healers, AYUSH)
9. Where do you refer patients for screening?
10. Where do you refer patients for diagnosis?
11. How long does it take for screening results?
12. Best methods to screen cancers: breast & cervix.
13. Where do you refer patients to seek treatment?
14. Do patients get adequate family support?
15. Do patients get adequate social support?
16. What are the questions patients pose if they test positive?
17. How many camps did you conduct /participate exclusively for Breast CA and CA uterine cervix?
18. How to improve patients' mobility to screening
19. Provider role and experiences providing cancer care
20. Provider perspectives on strategies improving cancer care beyond treatment.

ANNEXURE IV – GANTT CHART (EXECUTION)

TASKS COMPLETED	OCTOBER	NOVEMBER	DECEMBER	JANUARY	FEBRUARY	MARCH	APRIL	MAY
Ethical Clearance	█							
Induction & Orientation	█							
Sampling and Selection of participants	█							
Data Collection tool & Piloting	█							
Conduct of study	█	█	█	█				
Data Entry and Coding			█	█	█			
Analysis & Expert review			█	█	█	█	█	
Report writing				█	█	█	█	
Final submission							█	█

ANNEXURE V – STUDY SITE PHOTOS

1) Experts Meeting – September 2021



2) Project Site – Oncology ward, GRH, Chennai



17-12-2021 10:20



12-10-2021 13:03



(During Focus Group Discussion I)



(During Focus Group Discussion II)



(During In-Depth Interview)

3) Project Site – Gynaecology OPD, IOG, Chennai





(During In-Depth Interview among Non-cancer participants)



4) Project Site – Cancer Institute (WIA), Adyar, Chennai





(During In-depth Interview)

**5) Project Site – Arignar Anna Regional Cancer Hospital,
Kancheepuram (For Stakeholder interview)**



6) Project Site – Radiation Oncology ward, MMC, Chennai



(During Stakeholder Interview)

7) Experts Meeting (Virtual) – January 2022.

