

# Barriers and Enablers for Breast Cancer Screening Among Women in India

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A REVIEW AND EMPIRICAL ANALYSIS

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# Barriers and Enablers for Breast Cancer Screening Among Women in India – A Review and Empirical Analysis

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Science in Public Health

by

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Signature 

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## Abstract

**Introduction:** In India, an estimated 178,361 new breast cancer (BC) cases are identified annually and 90,408 succumb to BC each year. Despite India's national programmes to tackle the growing burden of BC, only 0.44% of women have ever undergone BC screening. The objective of this study was to explore barriers and enablers of BC screening uptake in India, focusing on role of women's empowerment and health system factors.

**Methodology:** A literature review was performed to identify factors affecting BC screening uptake in India, followed by secondary data analysis of women's dataset from NFHS-5 (2019-2021). Descriptive statistics, bivariate, and multivariable analysis were performed using Stata (v17.0).

**Results:** Lack of awareness, non-availability of healthcare infrastructure, and culture-appropriate healthcare workforce were commonly identified barriers in literature review. 707,119 women aged 15 to 49 years who had responded to 'ever having undergone breast examination' for cancer screening in NFHS-5 were included in study. Women with decision-making autonomy were significantly more likely to undergo BC screening than women who did not take their own decisions regarding healthcare or family visits. When adjusted for socio-demographic variables, positive association was seen between BC screening uptake and women without financial constraints for health services (AOR:1.18; 95%CI:1.08-1.30) and for whom distance to health center was non-problematic (AOR:1.13; 95%CI:1.02-1.26).

**Conclusion:** Reduced cancer awareness in the population and healthcare professionals, limited women's autonomy, and health system inadequacies contribute to lower BC screening uptake. Multi-dimensional strategies involving community, media, and technology are essential to reduce the burden of BC in the country.

**Keywords:** Breast cancer, Cancer screening, India, Barriers, Enablers

**Word count:** 10,778

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## List of Abbreviations

AB-HWC	Ayushman Bharat Health and Wellness Center
AOR	adjusted odds ratio
ASHA	Accredited Social Health Activist
ANM	Auxiliary Nurse Midwives
BC	breast cancer
BSE	breast self-examination
CBE	clinical breast examination
CHC	community health centre
CHW	community health worker
CI	confidence interval
DHS	Demographic Health Survey
FNAC	fine needle aspiration cytology
GoI	Government of India
HCP	healthcare provider
IARC	International Agency for Research on Cancer
ICMR	Indian Council of Medical Research
LHV	Lady Health Visitor
MoHFW	Ministry of Health and Family Welfare
NCCP	National Cancer Control Programme
NCDs	non-communicable diseases
NCRP	National Cancer Registry Programme
NFHS	National Family Health Survey
NP-NCD	National Programme for Prevention and Control of Non-Communicable Diseases
PHC	primary health centers
RCT	randomized controlled trial
SES	socio-economic status
SM	screening mammography
TN	Tamil Nadu
UHC	universal health coverage
UT	union territories
WHO	World Health Organization

## Key Terms

**Cancer screening:** The systematic application of a screening test for a specific cancer in an asymptomatic population to detect and treat cancer or pre-cancers before they become a threat to the well-being of the individual or the community. Early detection includes screening and early diagnosis.<sup>1</sup>

**Early-stage and late-stage cancer:** *Early-stage breast cancer* has not spread beyond the breast or the axillary lymph nodes. *Late-stage* is a term used to describe cancer that is far along in its growth and has spread to other lymph nodes or other places in the body.<sup>2</sup>

**State:** In India, the state government is considered the second tier of administration and is responsible for implementing national policies and programmes at the state level.<sup>3</sup>

**Anganwadi worker:** A woman employed to provide additional and supplementary healthcare and nutritional services to children and pregnant women under the Integrated Child Development Services Scheme.<sup>4</sup>

## Acknowledgment

**I wholeheartedly thank and dedicate this thesis to**

My family who helped me dream,

My friends who made sure I had fun while pursuing the dream,

My facilitators and advisors who nurtured the dream,

And God who protected me while I lived the dream.

It takes a village, they said. It indeed did. A global village.



# 1. Introduction and Background

## 1.1 Breast cancer – The burden of disease

Breast cancer (BC) is the most common cancer globally (figure 1), accounting for 24.5% of the global cancer incidence in women (figure 2).<sup>5</sup> As per the International Agency for Research on Cancer (IARC), 2.26 million new cases of BC were estimated worldwide in the year 2020 alone (figure 2). To this, India contributes 178,361 new BC cases annually, making BC the most common cancer in Indian women (figure 3a).<sup>5</sup> BC is also the leading cause of cancer death among women worldwide and in India. Globally, an estimated 684,996 women succumb to BC every year of which over 90,000 of them are in India alone (figure 3b).<sup>5</sup> Epidemiological trends in India show an increase in BC incidence and mortality over the years.<sup>6</sup> While BC is generally known as a disease affecting women above the age of 50 years, BC cases are increasingly being diagnosed in younger pre-menopausal in Indian women, a decade younger than that is observed in Western women.<sup>6</sup>

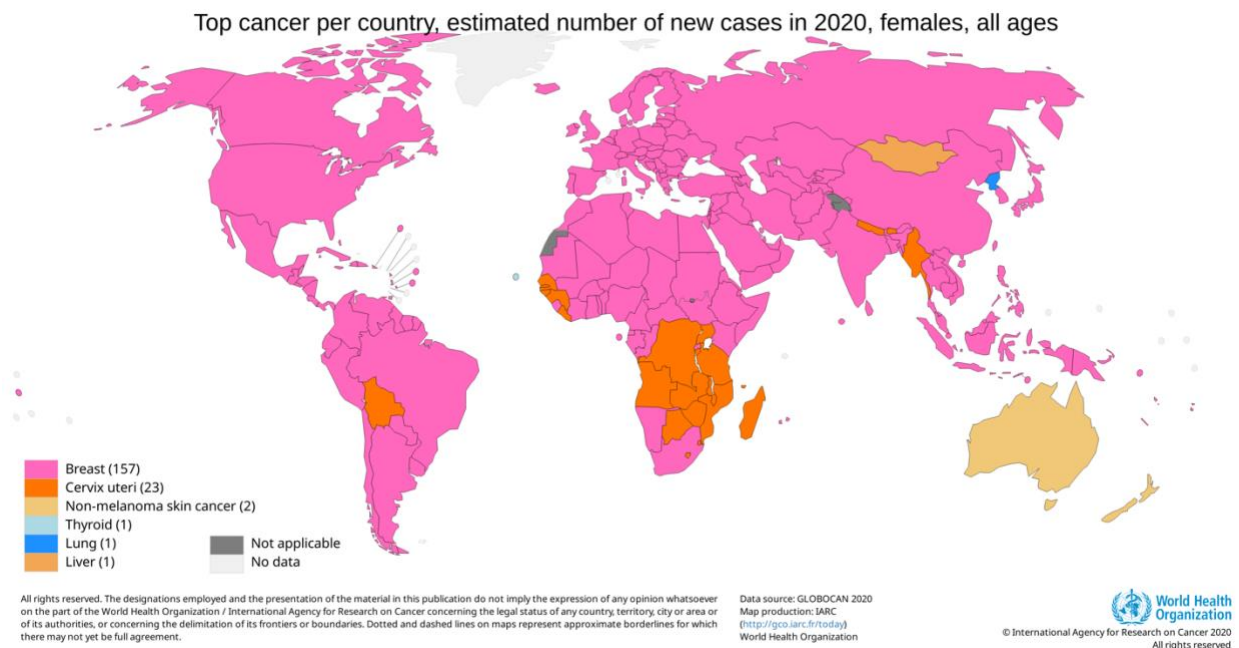


Figure 1: Global burden of breast cancer among all females, 2020.<sup>5</sup>

Estimated number of new cases in 2020, World, females, all ages

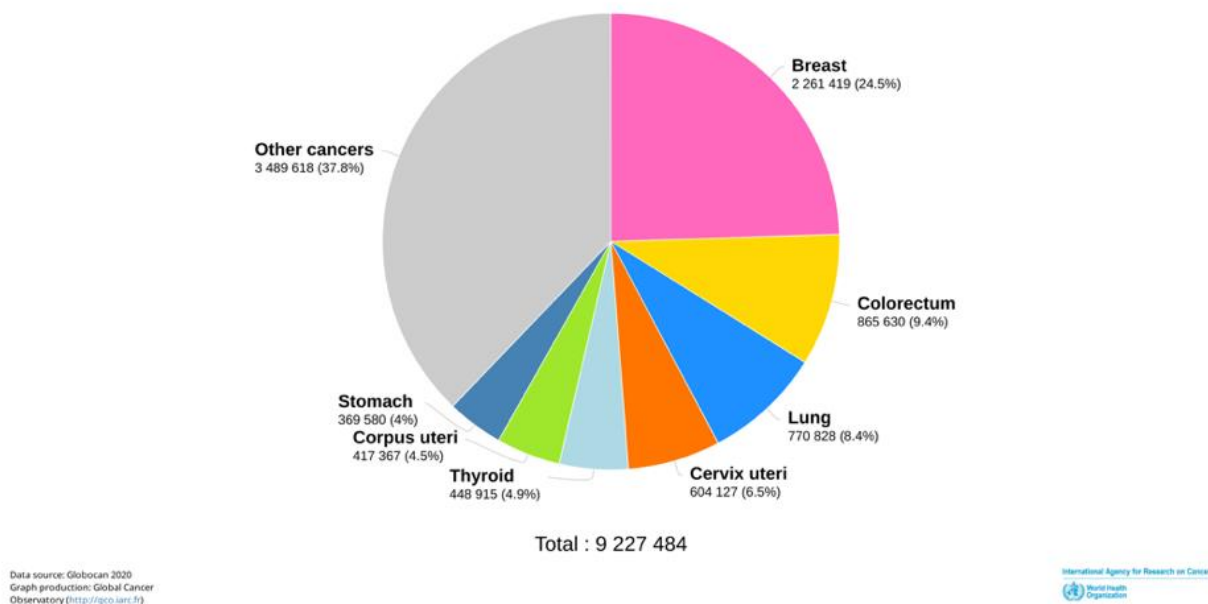


Figure 2: Global burden of cancers in females: estimated incidence in 2020.<sup>5</sup>

The mortality-to-incidence ratio is a high 1:2 in India (figure 3).<sup>5</sup> One of the major reasons for this high 50% mortality rate in India is the fact that women generally reach a hospital for treatment only in the later [stages](#) of cancer. A mere 4% reach hospitals when they are in stage 1 or early-stage of the disease. When detected and treated early, BC is associated with lesser morbidity and treatment costs, while improving life expectancy as compared to BC detected in later stages.<sup>7</sup>

BC is a multifactorial disease and its risk factors are classified as modifiable and non-modifiable. Some of the risk factors that may increase the risk of BC (in no specific order) are older age, family history of BC or ovarian cancer, prior diagnosis of non-cancerous breast lesions, obesity, presence of BRCA mutation, smoking, and alcohol consumption among others.<sup>8</sup> However, the incidence and mortality of BC are less dependent on the modification of risk factors and is best reduced by an efficient [screening](#) programme that enables early detection of BC.<sup>7</sup>

Estimated number of new cases in 2020, India, females, all ages

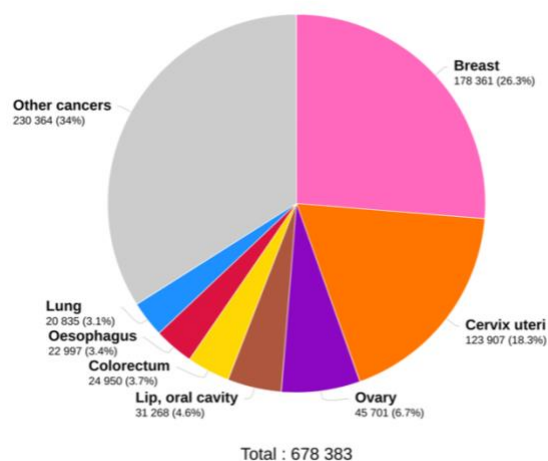


Figure 3a

Estimated number of deaths in 2020, India, females, all ages

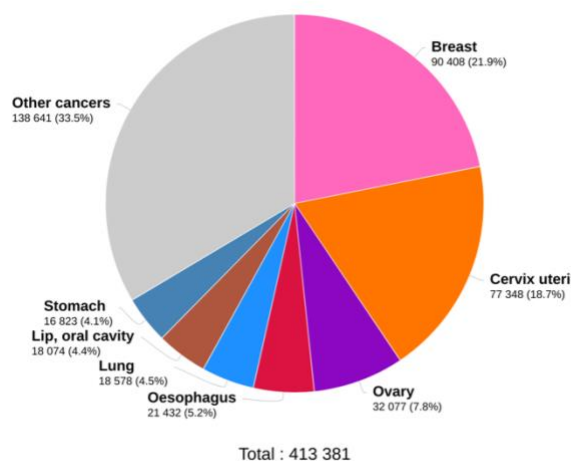


Figure 3b

Figure 3: a) Estimated number of new cancer cases in Indian women in 2020  
b) Estimated number of cancer deaths in Indian women in 2020

## 1.2 Indian health system – An overview

India is a federal union of 28 [states](#) and 8 union territories (UTs), which are further divided into districts and other smaller administrative units. The subject of health is constitutionally divided between Central and State governments. The formulation of policies and regulation of health insurance is entirely under the Central government. “Public Health, Sanitation, Hospitals, and Dispensaries” is under State governance. Thus, the “legislation, vision and financing, and delivery of health-care services” are largely under the purview of the State government. Social Health Insurance is on the concurrent list, which means that it falls under the jurisdiction of both the Central and State governments.<sup>3</sup>

India has a mixed healthcare delivery mechanism and sectors – public, for-profit private, and not-for-profit private sectors. The public sector, which includes both preventive and curative services is provided at multiple levels. At the primary level, sub-centers serve a population of 3,000-5,000 and primary health centers (PHCs) serve a population of 20,000-30,000. At the secondary level community health centers (CHCs) serve a population of 80,000-120,000 and then the district hospitals that serve the population of a district. At the tertiary level, medical colleges and state-level super-specialty hospitals provide care. Since there is no gatekeeping mechanism in place,

secondary and tertiary-level centers also deliver primary care, often leading to crowding at these hospitals.<sup>3</sup>

The private sector is the major healthcare provider in India. Most out-patient visits (around 70%), over half of the in-patient events (about 58%), most of the medicines dispensed (about 90%), and diagnostic services are provided by the private sector. Predominantly based on a fee-for-service model, the private sector is not well-regulated and hence has non-standardized quality of care and costs. Insurance coverage for all has been a challenge due to the larger proportion of the Indian population being employed in the informal sector. Thus, there is low financial protection from catastrophic health expenditures. As a result, the health-seeking behavior of the population depends largely on the individual's/family's financial situation.<sup>3</sup>

### 1.3 India's battle against cancer

India launched a National Cancer Control Programme (NCCP) in 1975 to equip cancer hospitals with equipment for treating cancer. In 1982, National Cancer Registry Programme (NCRP) was set up to create a cancer database via population and hospital-based registries. In 1984, the focus of NCCP was shifted to prevention, early detection, and diagnosis of cancer at the district level. Since most non-communicable diseases (NCDs) including cancer are linked with common behavioral risk factors, the Ministry of Health and Family Welfare (MoHFW) in India launched the 'National Programme for Prevention and Control of Non-Communicable Diseases' (NP-NCD) to integrate NCD interventions. Launched under the umbrella of India's flagship National Health Mission, a major agenda of this programme was the strengthening of outreach services through local community health workers (CHWs) known as Accredited Social Health Activists (ASHAs).<sup>9</sup>

The MoHFW, Government of India (GoI) provided an operational framework in 2016 recommending the screening of all women aged between 30 and 65 years for breast, cervical, and oral cancers.<sup>10</sup> This framework complemented the 3<sup>rd</sup> revised National Health Policy in 2017 which targeted "to reduce premature mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases by 25% by 2025" as a step towards achieving universal health coverage (UHC). The key outcome of the policy is the Ayushman Bharat programme, which had two main objectives – i) to expand the PHCs and make them more comprehensive for countering

the double burden of communicable and NCDs, and ii) to provide financial protection for secondary and tertiary care services.<sup>11</sup>

As of December 2022, over 150,000 existing sub-centers and PHCs have been revamped to now become the Ayushman Bharat Health and Wellness Centers (AB-HWCs). These centers have been equipped to include the screening of BC and other common communicable and non-communicable diseases.<sup>12,13</sup> The first level of cancer screening is to be performed by Auxiliary Nurse Midwives (ANMs) or staff nurses at the AB-HWCs. For BC, a clinical breast examination (CBE) is recommended to be done once every 5 years and if necessary, referred to a surgeon at a CHC or district hospital for confirmation via breast ultrasonography and/or histopathological examination.<sup>10</sup>

#### 1.4 Breast cancer screening methods and guidelines

**Breast self-examination (BSE)**<sup>7</sup>: BSE is a systematic visual and tactile examination of breasts performed by women themselves. Although training women to perform BSE is not recommended as a public health approach, it is the easiest of BC screening methods to advocate as it involves no healthcare personnel or equipment. The examination requires privacy, which is sometimes hard to find, especially in rural India that have smaller houses.

**Clinical breast examination (CBE)**: CBE is also a thorough and systematic visualization and tactile palpation of breasts done in sitting as well as supine positions by doctors or trained primary healthcare professionals. CBE is a cost-effective solution for detecting palpable lumps as it does not require a specific device. While its specificity is as high as 94% to 99%, it suffers from low sensitivity ranging between 28% to 54%. It is also a subjective test, and its contribution to mortality reduction is largely unknown.<sup>7,14</sup> The World Health Organization (WHO) recommends CBE for screening BC in women aged 50 to 69 years in limited-resource settings.<sup>1</sup>

**Screening mammography (SM)**: SM is a radiographic imaging method that can detect non-palpable breast lumps at an early stage and is considered the gold standard for early BC detection.<sup>15,16</sup> SM has demonstrated a 23% reduction in BC mortality through randomized controlled trials (RCT).<sup>17</sup> The sensitivity of SM varies from 64% to 90% and specificity ranges

between 82% to 93%.<sup>7</sup> The WHO recommends biennial screening with mammography for women aged 50 to 69 years in well-resourced settings.<sup>1</sup> In India, where BC screening is recommended at district hospitals, there are just 55 mammography machines at Government district hospitals to cater to 763 districts.<sup>18</sup> The mammography machines in private super-specialty hospitals are expensive.<sup>19</sup>

**Ultrasonography:** Breast ultrasonography has demonstrated a sensitivity of over 75% in women aged 40 to 49 years with dense breasts and hence, has been suggested as an effective alternate screening facility in low-resource countries. The overall sensitivity of ultrasonography is 53% to 67% and specificity is 89% to 99%.<sup>7</sup> However, India has a unique problem of fetal sex determination that has led to alarming numbers of female feticides. The Pre-Conception and Pre-Natal Diagnostic Techniques Act, 1994, bars a clinician from revealing the sex of the fetus.<sup>20</sup> The legal implication of this act means an ultrasound machine cannot be used in mobile or makeshift clinics, and hence its use as a portable device in a community-based screening programme is not a feasible option for screening BC in India.

#### Breast cancer screening guidelines

There are many guidelines and recommendations for BC screening, including European guidelines, guidelines by the United States Preventive Services Task Force, the American Society of Clinical Oncology, and the WHO. The WHO has recommendations based on age and setting. In 'well-resourced settings', WHO recommends an organized, population-based mammography screening programme for women aged 50 to 69 years every two years. In 'limited resource settings with weak health systems' where women are often diagnosed in late stages and mammography screening programmes do not exist as it is not cost-effective or feasible, WHO suggests using the CBE method for BC screening.<sup>1</sup>

The operational framework put forth by the MoHFW, GoI in 2016 mentions that while screening women above 40 years yields higher, for "programmatic and operational" reasons, the age for screening begins at 30 years for all common cancers. The framework is detailed in Figure 4.<sup>10</sup>

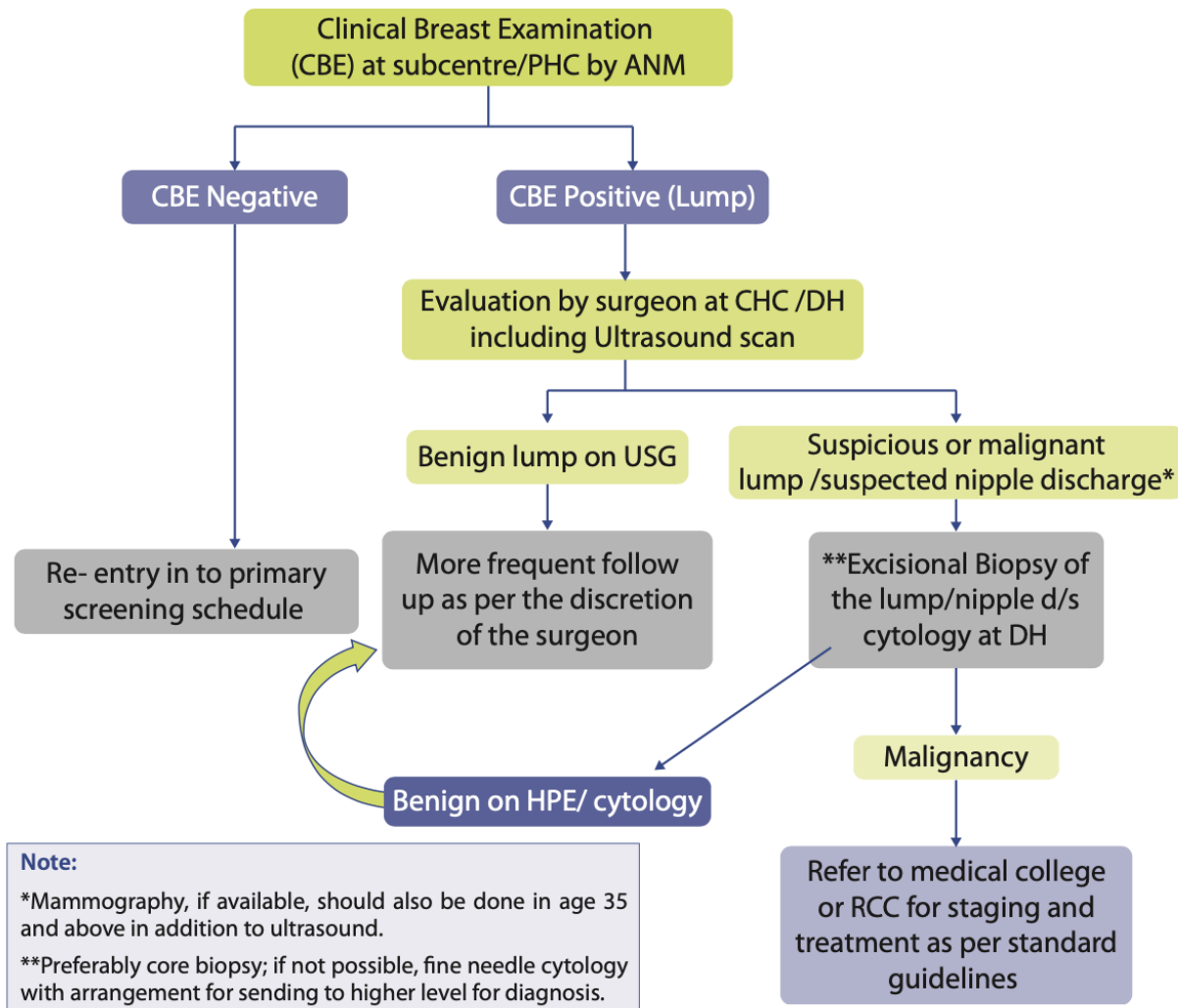


Figure 4: Flowchart depicting screening guidelines as recommended by Ministry of Health and Family Welfare, Government of India.<sup>10</sup>

(CBE, clinical breast examination; CHC, community health center; DH, district hospital; HPE, histopathological examination; PHC, primary health center; RCC, regional cancer center)

While the framework incorporates WHO’s suggestion of screening by CBE at sub-centers and PHCs, it also suggests the use of mammography and ultrasonography, when available, in women aged 35 to 65 years. The Indian Council of Medical Research (ICMR) recommends a triple assessment when a woman presents with symptoms – a CBE, mammography or ultrasonography, and histopathological assessment either by fine needle aspiration cytology (FNAC) or core biopsy.<sup>21</sup>

### 1.5 Problem statement and justification

Despite initiating cancer control programmes since 1975, cancer screening uptake has been very minimal. As per data from the 5<sup>th</sup> National Family Health Survey (NFHS-5) in 2019-2021, the BC screening uptake in women aged between 15 and 49 years was less than 1%.<sup>22</sup> While the NFHS-5 has asked the critical question of whether women have undergone BC screening, this question was not followed by the reason(s) for not getting the screening done.

The factors influencing participation in BC screening programme could range from low levels of education and awareness, stigma, fear that the disease is incurable, marital status, religion, gender bias in decision-making, socio-economic status (SES), financial constraints, fear of catastrophic health expenditures, poor accessibility due to geographic location, and health system inadequacies.<sup>23,24</sup>

Only two studies have analyzed the NFHS-5 data for correlation between BC screening uptake and factors – namely geographic variation, SES, religion, marital status, education, women empowerment, and habits.<sup>25,26</sup> In a study by Sen et al, published in 2022, the SES and regional variation in BC screening in the full sample of women aged 15 to 49 years and sub-sample of women aged 30 to 49 years were analyzed. At the individual level, age, marital status, religion, social group, place of residence, health insurance, use of hormonal contraception, body-mass index, drinking habits, tobacco consumption, eating habits, regions, education, and media exposure were analyzed. At the household level, the variable analyzed was the economic condition assessed using the wealth index, which was derived from consumer durables, household amenities, and materials used for house construction. The results showed that BC screening was low in rural, poorer, younger women, with lower education status and that there was a similar pattern of BC screening uptake in both the full sample and sub-sample.<sup>25</sup>

Patil et al performed an ecological study, published in 2023, on women aged between 30 and 49 years (N=364,556) of the NFHS-5 data. Along with the SES, women's empowerment, and its effect on the uptake of BC screening was also assessed. The variables used for assessing SES were households with electricity, improved drinking water source, improved sanitation facility, using clean fuel for cooking, and literacy in women. Variables considered for assessing women's



empowerment were participation of women in decisions regarding healthcare for themselves, making major household purchases, and visits to their family and relatives. Other variables considered were women working for the past 12 months and were paid in cash, women owning a house or land alone or with a husband, women who have a bank or savings account that they operate themselves, women having a mobile phone that they use themselves, and women who use hygienic protection methods during their menstrual period. The results demonstrated a moderate correlation between BC screening uptake and women's empowerment but with regional variation. Few states with higher rates of women empowerment had low BC screening uptakes and some states had higher uptake of screening even though there were lower rates of women empowerment and SES.<sup>26</sup>

These two studies<sup>25,26</sup> bring out a great level of understanding of the association between BC screening uptake and geographic variation, SES, religion, marital status, education, women empowerment, and habits based on NFHS-5 data ([Annexure 1](#)). However, women's empowerment-related variables listed in Table 1 have not yet been analyzed. Additionally, the NFHS-5 data has not yet been evaluated for health system factors (Table 1) and their effect on cancer screening uptake. This potentially could influence the approach, and allocation of resources, among others, in increasing BC screening uptake in a resource-constrained setting such as India. Considering that the Indian government would use its revamped AB-HWCs to also screen women for BC,<sup>13</sup> it is therefore of utmost urgency and importance to identify the factors influencing women's participation in the BC screening programme for improving early detection of BC.

**1.6 Research question:** What roles do women empowerment and the health system play in the uptake of BC screening among Indian women?

Table 1: List of variables from NFHS-5 data that have not yet been analyzed for associations with BC screening uptake

<b>Women empowerment</b>	<b>Health system-related factors</b>
Getting medical help for self – getting permission to go; getting money needed for treatment; not wanting to go alone to the health facility	Getting medical help for self – distance to health facility; having to take transport to reach health facility
Usually allowed to go to the health facility	Met with an ANM or LHV or <a href="#">Anganwadi worker</a> /ASHA/CHW in last 3 months
Reading newspaper or magazine; listening to radio; watching television	Services/matters talked about in last 3 months: disease prevention
	Service went for in last 3 months: disease prevention

ANM, Auxiliary Nurse Midwife; ASHA, Accredited Social Health Activist; CHW, community health worker; LHV, Lady Health Visitor.

## 2. Study Objectives

### 2.1 General objectives

To explore the role of women's empowerment and the health system in the uptake of BC screening among Indian women and inform national public health policymakers and strategists to design an approach for increasing the BC screening and early detection rates in the country.

### 2.2 Specific objectives

1. To explore existing knowledge regarding the barriers and enablers in the uptake of BC screening in India
2. To identify associations between predictor variables and BC screening uptake as per NFHS-5 data
3. To disseminate findings and recommendations to national public health policymakers and state strategists on designing an approach for increasing BC screening and early detection rates in the country

### 2.3 Hypothesis

The low uptake of BC screening among Indian women may be associated with women's empowerment and factors related to the health system.

### 3. Methodology

A two-step methodology was followed for the purpose of this study. First, a literature search regarding barriers and enablers in the uptake of BC screening in India was performed, followed by quantitative analysis and interpretation of NFHS-5 data.

#### 3.1 Literature search

A literature search was performed to explore factors that are associated with BC screening uptake in India. The keywords listed in [Annexure 2](#) were used to search for peer-reviewed publications in the VU library, PubMed, and Google Scholar. Considering that the cancer screening guidelines were published in 2016 by GoI,<sup>10</sup> articles published since 2016, in the English language, and relevant to the disease (BC) and region (India) were included in the literature review. The snowballing technique was employed to gather more publications for individual factors affecting BC screening uptake.

#### 3.2 Quantitative analysis

##### 3.2.1 Data source

The 2019-2021 NFHS-5 data was used to perform the secondary data analysis of the predictor variables identified from the literature search. The survey data from the NFHS-5 survey is housed with Demographic Health Survey (DHS). The DHS survey is a nationally representative survey that collects information on various aspects of health, including reproductive health, women empowerment, and access to healthcare services.

##### 3.2.2 Ethical consideration

This study used a secondary dataset which is freely available on the DHS website.<sup>27</sup> The data was collected by the International Institute for Population Sciences. The survey agencies have complied with the host country's Institutional Review Board and have obtained prior consent from respondents. The data has been anonymized and hence, does not require ethics clearance.

### *3.2.3 Study design and sample size*

Individual-level data were obtained from the 'women's file' of NFHS-5. It contained demographic information, information regarding utilization of maternal and child health, screening of common cancers and other NCDs, women's status and empowerment, health system factors, social media usage among others. The NFHS-5 interviewed 724,115 women aged 15 to 49 years. Among them, information regarding 'ever having undergone breast examination' for cancer screening was available for 707,119 women. The quantitative analysis in this study was performed for these 707,119 women only. The terms 'study population' and 'respondents' have been used interchangeably in this thesis.

### *3.2.4 Outcome and predictor variables*

**Outcome variable:** 'Having ever undergone a breast examination' was the dependent variable of the study which had binary values – 'yes' and 'no'.

**Predictor variables:** The following variables, some of which have already been referred to in Table 1 in Chapter 1, will be analyzed:

- i) **Women's empowerment** was assessed based on decision-making and movement autonomy derived from three variables – decision-maker on spending respondent's earnings, respondent's healthcare, and respondent's visit to her family or relatives. If decisions were taken by the husband/partner alone or some other person, it was categorized as 'other than respondent'. The questionnaire containing information regarding women's empowerment was administered to only a subsample of NFHS-4 households selected for the state module.
- ii) **Personal barriers** were assessed based on the ease of 'getting medical help for self' that was derived from three variables – getting permission to go to a health facility, getting money needed for treatment, and not wanting to go alone to a health facility.
- iii) **Health system barriers** were assessed based on the ease of 'getting medical help for self' derived from four variables – distance to health facility, having to take transport to health facility, concern of no healthcare provider (HCP), and concern of no female HCP.

Both personal and health system barriers were marked based on the respondent's perception of the intensity of the problem – 'small problem', 'big problem', or 'not a problem'. As these responses can be subjective and for the sake of this analysis, 'small problem' and 'big problem' were combined and recategorized to 'Is a problem'.

- iv) **Health system enablers** were assessed based on communication of the respondents with health workers, health promotion activities, and accessing of disease prevention services 3 months prior to the interview.

#### Socio-demographic variables:

- i) **Age:** Since GoI guidelines recommend BC screening for women aged 30 years and above, the study sample was recategorized as women aged below 30 years (15 to 29 years) and women aged 30 years and above, which was further grouped as 30 to 39 years and 40 to 49 years.
- ii) **Place of residence:** Urban or rural as defined by DHS/NFHS-5
- iii) **Region:** Based on NFHS-5 report, the states and UTs of India were grouped according to their geographical location as Central, East, North, North-east, South, and West India ([Annexure 3](#)).
- iv) **Religion:** Apart from India's three major religions of Hindu, Muslim, and Christianity, the rest of the religions were grouped as 'Others'.
- v) **Educational attainment:** For the sake of the study, women who did not receive any education or received only primary education were grouped into one category.
- vi) **Marital status:** For the sake of the study, women with widowed, divorced, or separated statuses were merged into one category.
- vii) **Occupation:** The questionnaire containing information regarding women's occupations was administered to only 15% of randomly selected households.

#### 3.2.5 Statistical analyses

Using the NFHS-5 data, descriptive, bivariate, and multivariable analyses were performed. Descriptive statistical analysis was performed to describe the distribution of outcome and predictor variables. Pearson's chi-square statistic test and odds ratio (OR) with 95% confidence

intervals (CI) were used to examine the associations between each variable and BC screening uptake in the bivariate statistical analysis.

As part of the multivariable analysis, logistic regression models were applied to examine the adjusted association between socio-demographic variables, personal and health system barriers, and BC screening uptake. The women empowerment, occupation, and health promotion variables were not part of the logistic regression model as that data was not available for the entire study population. The logistic regression model included the following:

- i) Socio-demographic variables: age, marital status, education, place of residence, region, and religion
- ii) Personal barriers to 'getting medical help for self' – getting permission to go to the health facility, getting money for health services, and not wanting to go alone to health facility
- iii) Perceived health system barriers to 'getting medical help for self' – distance to health facility, needing transport to health facility, lack of HCPs in general and female HCPs in particular

The logistic regression results were presented by the estimated adjusted odds ratio (AOR) with 95% CI. All the statistical analyses were performed using Stata version 17.0<sup>1</sup> (StataCorp LP, College Station, TX, USA).

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<sup>1</sup> ChatGPT was used for generating a few Stata commands.

## 4. Results

### 4.1 Barriers and enablers for breast cancer screening among women – Evidence from literature

The barriers and enablers for BC screening are diverse and intricate, spanning various aspects of social determinants of health such as personal factors, social influences, cultural norms, economic circumstances, and organizational challenges. These factors can either be an obstacle impeding or an enabler improving women's access to BC screening across different contexts and levels. For this study, factors affecting the uptake of BC screening in India were categorized into personal factors, socio-cultural influences, SES and financial constraints, women's empowerment, and health system factors. However, these factors are interlinked and often overlap and hence, will be presented in combinations.

#### *4.1.1 Personal factors and sociocultural influences*

Lack of awareness about BC and its risk factors, leading to myths and misconceptions about BC, and lack of information about BC screening services or facilities were the most prominent barriers to the uptake of BC screening services.<sup>28–42</sup> Psychosocial barriers such as fear of cancer diagnosis, fear of treatment procedures and associated high costs<sup>28–30,32–34,37,39,40,43</sup>, and social stigma<sup>29,30,32,34–37,39,40,43</sup> also deter women from accessing the services. Women felt shy and embarrassed to get breast examinations done,<sup>33,34,37,39,40</sup> even when services were available.<sup>35</sup> This is probably because culturally Indian women are expected to dress modestly to cover their private body parts. Studies in rural women showed that lack of privacy to perform BSE was a barrier to early detection of BC.<sup>31,35</sup> The lack of privacy is probably due to larger joint families living together in smaller houses, which is a norm in rural India.

In India, the woman is responsible for the general functioning of the house – from cooking to cleaning to childcare. Consequently, lack of time to visit a hospital due to family obligations, lack of family or spousal support to go to the hospital, prioritizing family and social responsibilities before their own, fear of diagnosis affecting family, and becoming a 'burden' on the family are some of the often-cited socio-cultural barriers in accessing healthcare services on time.<sup>28,30,32,34,36,37,39,40</sup>



The most prominent enabler for increased uptake of BC screening services is increased awareness not just in women, but also among male members of the family.<sup>32–35,41,44</sup> Women tend to participate in their own healthcare decisions more when motivated by male family members,<sup>33,35,36</sup> female employers,<sup>32,33,35,36</sup> younger educated children, religious leaders,<sup>32</sup> and women doctors<sup>36,37</sup> or when they have family member(s) affected by BC<sup>31,32</sup>. However, in a quantitative study on 502 rural women, there was no significant association between performing BSE and family history of BC.<sup>31</sup> This is probably because BC is seen as taboo or a ‘curse’ and hence, BC patients may not talk about their disease openly. Also, since most cases are detected in the late stages, it is unlikely that HCPs would talk about BSE and its role in early detection to BC patients.

#### *4.1.2 Socio-economic status and financial constraints*

In an analysis of NFHS-4 data of 699,686 Indian women aged 15 to 49 years, the wealth index was positively correlated with BC screening uptake.<sup>45</sup> Similar results of the association of poor wealth with low uptake of BC screening services have been reported by other studies.<sup>25,35,46</sup> Financial constraints for traveling to access health facilities or diagnostic tests and opportunity cost lost were reported as barriers to accessing BC screening services.<sup>28–30,32–35,37,39–41</sup> In a quantitative study of 502 rural women, possession of television or radio at home was stated to be a facilitator for learning BSE.<sup>31</sup>

Geographically, South, West, and North India had higher uptake of BC screening as compared to their counterparts in Central, East, and North-East India. This difference in BC screening uptake in these regions was explained by the poor wealth index in these regions.<sup>45</sup> The analysis of NFHS-5 data has shown that BC screening was high in urban populations and in women with higher education status.<sup>25</sup> A literature review assessed the levels of awareness of BC risk factors in 7,066 Indian women aged 15 to 70 years from 13 studies published over a span of 8 years. The results revealed that there were low levels of awareness regarding risk factors of BC in Indian women, irrespective of their education or SES. Even HCPs had limited awareness regarding BC risk factors.<sup>44</sup> This difference between education and cancer literacy in both the general population

and HCPs indicates that probably education alone cannot be used as a proxy for the level of cancer awareness.

#### *4.1.3 Women's empowerment*

Women's empowerment has been assessed through various parameters such as literacy, financial autonomy, possession of mobile phones, and decision-making autonomy. While the NFHS questionnaires were formulated to evaluate women's autonomy in the reproductive health context, these variables can be extrapolated and analyzed for their role in BC screening uptake. In analyses of earlier NFHS data, there has been a positive correlation between women's empowerment and its relation to the utilization of BC screening services<sup>45,46</sup> and reproductive health outcomes.<sup>47,48</sup>

In a qualitative study in South Indian women, about 50% of women mentioned that "husbands did not allow them to go for screening".<sup>37</sup> Analysis of NFHS-4 data showed a positive association between educated and financially independent women and the ability to make their own healthcare-related decisions.<sup>46</sup> While this correlation was not uniform across regions, a similar positive association was seen between literate women and women who self-operated their bank accounts and uptake of BC screening observation in the analysis of NFHS-5 data.<sup>26</sup>

On analysis of full sample of NFHS-5 data, no significant association was seen between BC screening uptake and women's empowerment variables of participation in household decisions, employment in the last 12 months and earned in cash, owning house/land alone or with a husband, using hygienic methods of protection during menstrual period or having a mobile phone for self-use.<sup>26</sup> Interestingly, these results differ in significance from those reported from sub-sample analysis of NFHS-4 data, where a significant positive correlation was observed between women using a mobile phone and their participation in screening.<sup>45</sup> The differing outcomes between the two studies could be attributed to the difference in sample size and age of the study population; women aged 15 to 49 years in the NFHS-4 study and women aged 30 to 49 years in the NFHS-5 study. It is plausible that women who do not possess their own mobile phones might rely on providing their children's phone numbers as contact information. This practice could lead to communication challenges, as children may not always pass on screening-

related information promptly, resulting in a loss-to-follow-up as seen in a cervical cancer screening study in rural South Indian women.<sup>49</sup>

A study done on 11,249 Swiss women demonstrated that opportunistic mammography-based screening was higher in women who lived with a (marital) partner than those who did not. However, the uptake was lower when there was gender inequality. Gender inequality was measured as the “gap between men and women in the time they allocate to unpaid work (domestic tasks), that is, the sexual division of unpaid work”.<sup>50</sup> Similar results were observed in a study done on 55,201 European women, where lower participation in BC screening was associated with gender inequality and low levels of education, irrespective of the screening strategy employed by a country.<sup>51</sup>

These results highlight the multifaceted and complex association between women's empowerment and BC screening uptake and require a comprehensive analysis while considering the interplay of confounding factors.

#### *4.1.4 Health system factors*

Health system factors, such as accessibility to health facilities, availability of infrastructure and healthcare workforce, and quality of service delivery are beyond the control of individuals or households and are relatively more amenable to modification compared to individual behavior. Thus, it becomes imperative to thoroughly examine the role of health system factors, and their impact on health-seeking behaviors, so that tailored approaches can be developed, and resources efficiently allocated, thereby optimizing cancer screening uptake.

The most common barrier to seeking healthcare services early was the distance to health facilities.<sup>29,30,33,34,36,37,39,45</sup> Transportation to the facilities, especially in difficult hilly terrains of north-east India, is a prominent factor for reduced accessibility of healthcare services. Lack of standard equipment and facilities to perform screening has also been cited as reasons for delays in providing care.<sup>28,36,37</sup>

The lack of female HCPs was the most common healthcare workforce-related barrier to the uptake of BC screening.<sup>30,34–37</sup> Misdiagnosis at first contact, usually at PHCs or private

practitioners,<sup>29,34</sup> leading to multiple visits to primary care providers results in a referral delay and thus, the presentation of cancer at a later stage. This could reduce the trust in HCPs, as reported in some studies.<sup>32,34,36,44</sup> The initial misdiagnosis could be attributed to a lack of knowledge amongst HCPs,<sup>37,39,40</sup> which also could be the reason why screening advice is not provided to the women visiting facilities.<sup>28,33</sup> In a study, almost 60% of 435 BC patients were not offered any investigations at first consultation; imaging (mammography or ultrasonography) or FNAC was offered to 30% of women and only around 10% of women were assessed as per ICMR standards of triple assessment.<sup>29</sup> A few studies have also reported increased waiting periods, and unapproachable HCPs as contributing factors to reduced BC screening uptake.<sup>29,37</sup>

Lack of knowledge about service availability,<sup>28,29</sup> the importance of early diagnosis, different screening methods, and the screening process<sup>28,49</sup> among women were some common barriers to BC screening uptake. While this lack of awareness could be considered a personal factor, health promotion, especially regarding health facilities and programmes is one of the responsibilities of the health system.

Empowering through awareness, mandatory screening policies along with financial support, and female HCPs are enablers for increased BC screening uptake.<sup>31-37</sup>

## 4.2 NFHS-5 data analysis

### 4.2.1 Descriptive statistics

For the study, data from 724,115 women aged between 15 to 49 years were obtained from NFHS-5. Among these, 707,119 (97.65%) women who responded to the question regarding whether they have ever undergone a breast examination were included in the analysis. Of them, 49.46% of respondents were aged between 15 to 29 years and remaining 50.54% of respondents were aged between 30 to 49 years. Table 2 presents the demographic characteristics of the study population.

*Table 2: Demographic characteristics of women aged 15 to 49 years in study population*

Demographic variables		No. of women (N=707,119)	%
Ever undergone breast examination	No	703,973	99.56
	Yes	3,146	0.44
Age group (years)	15-29	349,766	49.46
	30-39	195,158	27.60
	40-49	162,195	22.94
Place of residence	Urban	173,171	24.49
	Rural	533,948	75.51
Region	Central India	164,949	23.33
	East India	116,264	16.44
	North India	101,040	14.29
	North-East India	102,427	14.49
	South India	109,855	15.53
	West India	112,584	15.92
Religion	Hindu	533,521	75.45
	Muslim	87,825	12.42
	Christian	51,564	7.29
	Others	34,209	4.84
Educational attainment	No education	163,951	23.19
	Primary education	83,470	11.80
	Secondary education	361,385	51.11
	Higher education	98,313	13.90
Marital status	Never married	174,860	24.73
	Currently married	502,467	71.06
	Widowed/Divorced/Separated	29,792	4.21

As seen in Table 2 about three-fourths of the respondents resided in rural areas. While the study population was more or less evenly distributed among all regions of the country, Central India had the largest share of respondents. Most of the respondents (75.45%) identified themselves as Hindus, about half of the respondents had at-least secondary-level education, and 71.06% of respondents were currently married.

Occupation data were available for only 106,259 women due to the 15% subsampling of households. Most of the respondents (67.73%) were not employed; among those employed, 16.69% were employed in the agricultural sector, which is largely an informal sector (Table 3).

*Table 3: Respondents' occupation in study population, N = 106,259 women*

<b>Respondents' Occupation</b>	<b>No. of women</b>	<b>%</b>
Not working	71,974	67.73
Professional/technical/managerial	2,878	2.71
Clerical	462	0.43
Sales	2,010	1.89
Services/household and domestic	3,355	3.16
Agricultural	17,734	16.69
Skilled and unskilled manual	6,272	5.90
Other & don't know	1,574	1.48
<b>Total</b>	<b>106,259</b>	<b>100</b>

Women’s empowerment data collected from a subsample of 15% of households showed that most respondents made decisions regarding spending their earnings, their healthcare, and visits to their family along with their husbands/partners than on their own (Table 4). Almost 20% of the respondents were not involved in decisions regarding their own healthcare and 15% of the respondents didn’t have a say in how to spend their own earnings.

*Table 4: Women’s empowerment assessed based on decision-making and movement autonomy*

Variables related to decision-making and movement autonomy		No. of women	%
Person who usually decides how to spend respondent's earnings	Respondent alone	3,225	15.82
	Respondent along with husband/partner	14,094	69.15
	Other than respondent	3,064	15.03
	<b>Total</b>	<b>20,383</b>	100
Person who usually decides on respondent's health care	Respondent alone	7,269	9.64
	Respondent along with husband/partner	54,235	71.91
	Other than respondent	13,912	18.45
	<b>Total</b>	<b>75,416</b>	100
Person who usually decides respondent's visits to her family or relatives	Respondent alone	5,858	7.77
	Respondent along with husband/partner	55,799	73.99
	Other than respondent	13,759	18.24
	<b>Total</b>	<b>75,416</b>	100

The NFHS-5 data included information on factors that prevent women from getting medical help for themselves. In this study, these factors have been classified as personal and perceived health system factors and the results are presented in Table 5. More than one-third of the respondents find it difficult to get permission to go to a health facility. About half the respondents had financial constraints in accessing medical services and did not want to go to a health facility unaccompanied.

Concern that there is no HCP at the facility (68.24%), particularly a female HCP (63.20%), distance to health facility (60.52%), and having to take transport to reach the health facility (58.66%) were perceived as barriers to getting medical help for self.

*Table 5: Personal and perceived health system barriers and enablers to getting medical help for self, N=707,119 women*

Barriers and enablers to getting medical help for self		No. of women	%
<b>Personal Factors</b>			
Getting permission to go to a health facility	Not a problem	456,878	64.61
	Is a problem	250,241	35.39
Getting money needed for treatment	Not a problem	331,182	46.84
	Is a problem	375,937	53.16
Not wanting to go alone	Not a problem	347,334	49.12
	Is a problem	359,785	50.88
<b>Perceived Health System Factors</b>			
Distance to health facility	Not a problem	279,142	39.48
	Is a problem	427,977	60.52
Having to take transport to reach health facility	Not a problem	292,329	41.34
	Is a problem	414,790	58.66
Concern that there may not be any healthcare provider at facility	Not a problem	224,577	31.76
	Is a problem	482,542	68.24
Concern that there may not be a female healthcare provider at facility	Not a problem	260,238	36.80
	Is a problem	446,881	63.20



Field or house visits by health workers play a critical role as the initial point of contact between the health system and household members, particularly women; more so in semi-urban and rural communities. Generally, these visits are related to reproductive and maternal health, especially if an Auxiliary Nurse Midwife (ANM) or Lady Health Visitor (LHV) is involved. Table 6 summarizes the information related to the health workers' interaction with respondents and the outcome of these interactions in relation to disease prevention. Data for interaction with health workers were available from 707,109 respondents (10 respondents' data are missing; reason unknown).

In the last 3 months prior to data collection, an ANM or LHV met 19.70% of respondents and an Anganwadi worker or ASHA or CHW met 28.39% of respondents. During these interactions between healthcare workers in the community and respondents, 'disease prevention' was discussed with only 2.49% of the respondents. A further query of whether the respondents went for the service of 'disease prevention' was answered by 599,079 women of which only 0.29% of the respondents answered in the affirmative.

*Table 6: Contact of respondents with health workers and outcome related to disease prevention*

Health promotion-related variables		No. of women	%
Respondent met with ANM/LHV in last 3 months	No	567,841	80.30
	Yes	139,268	19.70
	<b>Total</b>	<b>707,109</b>	100
Respondent met with Anganwadi worker/ASHA/CHW in last 3 months	No	506,349	71.61
	Yes	200,760	28.39
	<b>Total</b>	<b>707,109</b>	100
'Disease prevention' talked about in last 3 months with respondent	No	689,512	97.51
	Yes	17,597	2.49
	<b>Total</b>	<b>707,109</b>	100
'Disease prevention' service sought in last 3 months by respondent	No	597,326	99.71
	Yes	1,753	0.29
	<b>Total</b>	<b>599,079</b>	100

ANM, Auxiliary Nurse Midwives; ASHA, Accredited Social Health Activist; CHW, community health worker; LHV, Lady Health Visitor

The NFHS-5 also collected information regarding media exposure and its frequency of usage (Table 7), which can be used for planning health promotion activities. Television was the most common medium (72.39%), followed by newspapers or magazines (31.5%), and radio (13.93%).

*Table 7: Frequency of media exposure in respondents, N=707,119 women*

Type of media exposure		No. of women	%
Reading newspaper or magazine	Not at all	484,376	68.50
	Less than once a week	133,869	18.93
	At least once a week	88,874	12.57
Listening to radio	Not at all	608,607	86.07
	Less than once a week	68,365	9.67
	At least once a week	30,147	4.26
Watching television	Not at all	195,261	27.61
	Less than once a week	154,751	21.88
	At least once a week	357,107	50.50

## Bivariate analysis

### 4.2.2 Socio-demographics influences

Table 8 shows the positive association between age and the uptake of BC screening. Women aged 40 to 49 years were 2.8 times significantly more likely to undergo BC screening than women aged 15 to 29 years. Figure 5 shows BC screening uptake per age group among those who underwent BC screening (n=3,146).

Table 8: Cross-tabulation of age and breast cancer screening uptake

Age groups	Ever undergone breast examination			
	No, n (%)	Yes, n (%)	Total, n	OR (95% CI), p value
15-29 years	348,881 (99.75%)	885 (0.25%)	349,766	Ref
30-39 years	98,557 (99.47%)	527 (0.53%)	99,084	2.25 (2.06-2.46), 0.00
40-49 years	256,535 (99.33%)	1,734 (0.67%)	258,269	2.82 (2.58-3.08), 0.00
<b>Total</b>	<b>703,973 (99.56%)</b>	<b>3,146 (0.44%)</b>	<b>707,119</b>	

Pearson  $\chi^2 = 616.2640$ ;  $p = 0.000$

CI, confidence interval; OR, odds ratio.

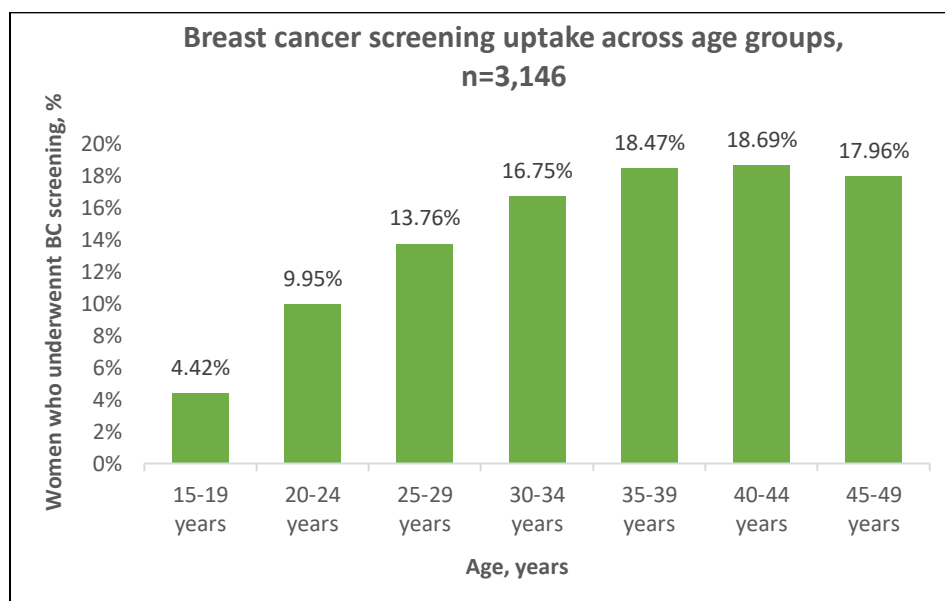


Figure 5: Breast cancer screening uptake among those who underwent BC screening across age groups, n=3,146

The percentage of BC screening uptake was higher in urban areas (0.68%) than in rural areas (0.37%) as seen in Table 9 (OR 1.87; 95% CI:1.74-2.00). Geographically, it appears that more South Indian women underwent BC screening than the rest of the country (Table 10). The associations were statistically significant.

Table 9: Cross-tabulation of place of residence and breast cancer screening uptake

Place of residence	Ever undergone breast examination			
	No, n (%)	Yes, n (%)	Total, n	OR (95% CI), p value
Urban	171,987 (99.32%)	1,184 (0.68%)	173,171	1.87 (1.74-2.00), 0.00
Rural	531,986 (99.63%)	1,962 (0.37%)	533,948	Ref
<b>Total</b>	<b>703,973 (99.56%)</b>	<b>3,146 (0.44%)</b>	<b>707,119</b>	

Pearson chi2 = 295.2951; p = 0.000

CI, confidence interval; OR, odds ratio.

Table 10: Cross-tabulation of the region and breast cancer screening uptake

Geographical region	Ever undergone breast examination			
	No, n (%)	Yes, n (%)	Total, n	OR (95% CI), p value
Central	164,446 (99.70%)	503 (0.30%)	164,949	Ref
East	116,077 (99.84%)	187 (0.16%)	116,264	0.0 (0.41-0.61), 0.00
North	100,802 (99.76%)	238 (0.24%)	101,040	0.81 (0.70-0.95), 0.01
North-East	102,104 (99.68%)	323 (0.32%)	102,427	0.98 (0.83-1.16), 0.84
South	108,340 (98.62%)	1,515 (1.38%)	109,855	4.34 (3.79-4.98), 0.00
West	112,204 (99.66)	380 (0.34%)	112,584	1.05 (0.89-1.23), 0.54
<b>Total</b>	<b>703,973 (99.56%)</b>	<b>3,146 (0.44%)</b>	<b>707,119</b>	

Pearson chi2 = 2.6e+03; p = 0.000

CI, confidence interval; OR, odds ratio.

Christian women (0.59%) appeared to have accessed BC screening significantly more than their Hindu (0.46%) and Muslim (0.32%) counterparts as seen in Table 11.

*Table 11: Cross-tabulation of religion and breast cancer screening uptake*

Religion	Ever undergone breast examination			
	No, n (%)	Yes, n (%)	Total, n	OR (95% CI), p value
Hindu	531,081 (99.54%)	2,440 (0.46%)	533,521	Ref
Muslim	87,548 (99.68%)	227 (0.32%)	87,825	0.69 (0.60-0.78), 0.00
Christian	51,529 (99.41%)	305 (0.59%)	51,564	1.29 (1.15-1.46), 0.00
Others	34,085 (99.64%)	124 (0.36%)	34,209	0.79 (0.66-0.95), 0.01
<b>Total</b>	<b>703,973 (99.56%)</b>	<b>3,146 (0.44%)</b>	<b>707,119</b>	

Pearson  $\chi^2(3) = 65.3826$ ;  $p = 0.000$

CI, confidence interval; OR, odds ratio.

As compared to women who were not educated or received up to primary education, women with secondary education were 1.3 times more likely and women with higher education were 1.7 times more likely to undergo BC screening (Table 12). The Pearson chi-square test of independence also revealed a significant association between BC screening uptake and education.

*Table 12: Cross-tabulation of educational attainment and breast cancer screening uptake*

Educational attainment	Ever undergone breast examination			
	No, n (%)	Yes, n (%)	Total, n	OR (95% CI), p value
Nil/primary education	246,534 (99.64%)	887 (0.36%)	247,421	Ref
Secondary education	359,724 (99.54%)	1,661 (0.46%)	361,385	1.29 (1.18-1.39), 0.00
Higher education	97,715 (99.39%)	598 (0.61%)	98,313	1.70 (1.53-1.89), 0.00
<b>Total</b>	<b>703,973 (99.56%)</b>	<b>3,146 (0.44%)</b>	<b>707,119</b>	

Pearson  $\chi^2(2) = 102.7048$ ;  $p = 0.000$

OR, odds ratio; CI, confidence interval.

Table 13 shows that BC screening uptake was significantly higher in widowed, divorced, or separated women (0.65%) as compared to married women (0.54%) and unmarried women (0.15%). This association between marital status and BC screening uptake is probably due to age. There is a higher possibility of unmarried women being in the younger age group of 15 to 29 years and most widowed, divorced, or separated women being in the older age group of 40 to 49 years (Figure 6).

Table 13: Cross-tabulation of marital status and breast cancer screening uptake

Current marital status	Ever undergone breast examination			
	No, n (%)	Yes, n (%)	Total, n	OR (95% CI), p value
Never Married	174,598 (99.85%)	262 (0.15%)	174,860	Ref
Currently married	499,778 (99.46%)	2,689 (0.54%)	502,467	3.59 (3.16-4.07), 0.00
Widowed/Divorced /Separated	29,597 (99.39%)	195 (0.65%)	29,792	4.39 (3.65-5.29), 0.00
<b>Total</b>	<b>703,973 (99.56%)</b>	<b>3,146 (0.44%)</b>	<b>707,119</b>	

Pearson  $\chi^2(2) = 465.6951$ ;  $p = 0.000$

CI, confidence interval; OR, odds ratio.

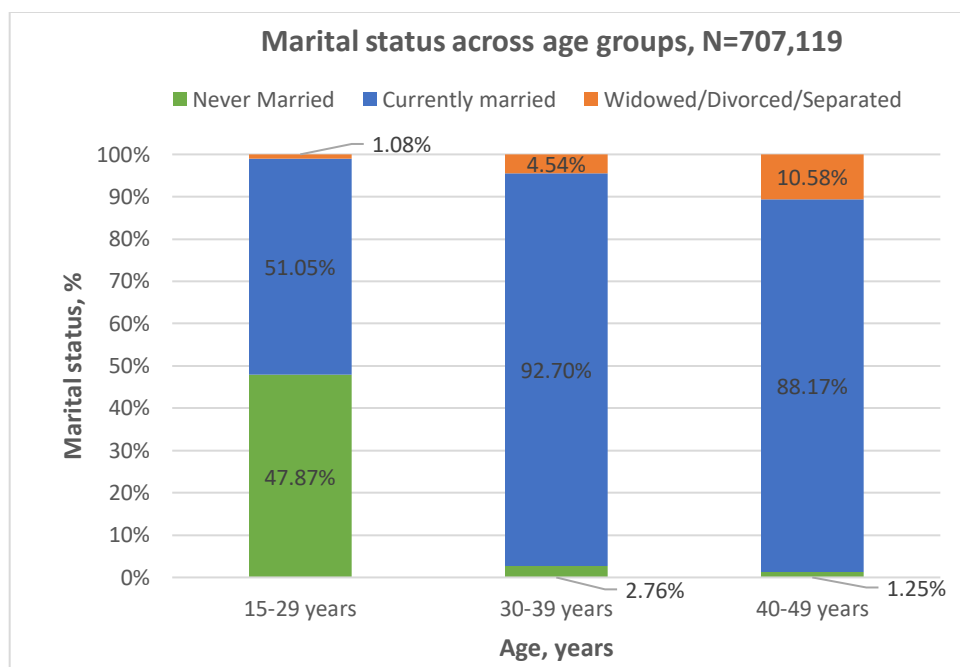


Figure 6: Marital status and age groups, N=707,119

#### 4.2.3 Personal barriers

Women who did not have a problem getting permission to visit a health facility, or getting money that was needed for treatment were more likely to undergo BC screening than women who didn't get permission or financial assistance (Table 14). Furthermore, women who didn't mind going to a health facility alone also were more likely to undergo BC screening than women who did not want to go to a health facility alone. All the associations were statistically significant.

Table 14: Cross-tabulation of personal barriers to 'getting medical help for self' and breast cancer screening uptake, N=707,119

Getting medical help for self		Ever undergone breast examination			OR (95% CI), p value	Pearson chi2, p value
		No, n (%)	Yes, n (%)	Total, n		
Getting permission to go to a health facility	Not a problem	454,698 (99.52%)	2,180 (0.48%)	456,878	1.24 (1.15-1.33), 0.00	30.3108 p = 0.000
	Is a problem	249,275 (99.61%)	966 (0.39%)	250,241	Ref	
Getting money needed for treatment	Not a problem	329,440 (99.47%)	1,742 (0.53%)	331,182	1.41 (1.31-1.51), 0.00	92.4823 p = 0.000
	Is a problem	374,533 (99.63%)	1,404 (0.37%)	375,937	Ref	
Not wanting to go alone to a health facility	Not a problem	345,679 (99.52%)	1,655 (0.48%)	347,334	1.15 (1.07-1.23), 0.00	15.3733 p = 0.000
	Is a problem	358,294 (99.59%)	1,491 (0.41%)	359,785	Ref	
<b>Total</b>		703,973 (99.56%)	3,146 (0.44%)	<b>707,119</b>		

CI, confidence interval; OR, odds ratio.

#### 4.2.4 Women's empowerment – Decision-making autonomy

Women's empowerment measured via decision-making autonomy and its relation to BC screening uptake is presented in Table 15. About 34,000 respondents had an occupation, yet due to 15% sampling, responses from only 20,383 respondents were available for decision-making authority on how to spend respondents' earnings. Although not statistically significant, women who have autonomy over their earnings were 1.6 times more likely to get BC screening done than

women whose earnings were spent based on others' decisions. Women who took their own healthcare decisions were 1.6 times more likely to undergo BC screening than women who were not involved in their own healthcare decisions. Similarly, women who took their own decisions to visit their family or relatives were twice as likely to undergo BC screening than women who were not part of the decision-making process. Both these results were statistically significant.

Table 15: Cross-tabulation of decision-making autonomy and breast cancer screening uptake

Decision-making autonomy		Ever undergone breast examination			OR (95% CI), p value	Pearson chi2, p value
		No, n (%)	Yes, n (%)	Total, n		
Who decides how to spend respondent's earnings	Respondent alone	3,194 (99.04%)	31 (0.96%)	3,225	1.64 (0.91-2.94) 0.09	2.9130 p = 0.233
	Respondent with husband/partner	13,987 (99.24%)	107 (0.76%)	14,094	1.29 (0.78-2.14) 0.31	
	Other than respondent	3,046 (99.41%)	18 (0.59%)	3,064	Ref	
	<b>Total</b>	20,227 (99.23%)	156 (0.77%)	<b>20,383</b>		
Who decides regarding respondent's healthcare	Respondent alone	7,216 (99.27%)	53 (0.73%)	7,269	1.61 (1.11-2.33), 0.01	6.8537 p = 0.032
	Respondent with husband/partner	53,945 (99.47%)	290 (0.53%)	54,235	1.18 (0.89-1.56), 0.23	
	Other than respondent	13,849 (99.55%)	63 (0.45%)	13,912	Ref	
	<b>Total</b>	75,010 (99.46%)	406 (0.54%)	<b>75,416</b>		
Who decides visits to respondent's family or relatives	Respondent alone	5,805 (99.10%)	53 (0.90%)	5,858	1.98 (1.38-2.86), 0.00	16.7124 p = 0.000
	Respondent with husband/partner	55,509 (99.48%)	290 (0.52%)	55,799	1.14 (0.86-1.49), 0.36	
	Other than respondent	13,696 (99.54%)	63 (0.46%)	13,759	Ref	
	<b>Total</b>	75,010 (99.46%)	406 (0.54%)	<b>75,416</b>		

CI, confidence interval; OR, odds ratio.



Women who were involved in making these decisions along with their husbands/partners were more likely to undergo BC screening than women who were not involved in the decision-making process. However, these results are not statistically significant.

#### 4.2.5 Perceived health system factors

##### 4.2.5.1 Health system barriers

Women who perceived distance to a health facility or having to take transport to a health facility as problematic were significantly less likely to get BC screening compared to those without such concerns. Women who share a concern that an HCP may not be at the facility, particularly a female HCP, were also significantly less likely to undergo BC screening (Table 16).

Table 16: Cross-tabulation of health system barriers to 'getting medical help for self' and breast cancer screening uptake

Getting medical help for self		Ever undergone breast examination			OR (95% CI), p value	Pearson chi2, p value
		No, n (%)	Yes, n (%)	Total, n		
Distance to health facility	Not a problem	277,670 (99.47%)	1,472 (0.53%)	279,142	1.35 (1.26-1.49), 0.00	70.7455 p = 0.000
	Is a problem	426,303 (99.61%)	1,674 (0.39%)	427,977	Ref	
Having to take transport to health facility	Not a problem	290,837 (99.49%)	1,492 (0.51%)	292,329	1.28 (1.19-1.37), 0.00	48.2418 p = 0.000
	Is a problem	413,136 (99.60%)	1,654 (0.40%)	414,790	Ref	
Concern of no healthcare provider	Not a problem	223,348 (99.45%)	1,229 (0.55%)	224,577	1.30 (1.22-1.40), 0.00	77.8295 p = 0.000
	Is a problem	480,625 (99.60%)	1,917 (0.40%)	482,542	Ref	
Concern of no female healthcare provider	Not a problem	258,880 (99.48%)	1,358 (0.52%)	260,238	1.38 (1.28-1.48), 0.00	55.0160 p = 0.000
	Is a problem	445,093 (99.60%)	1,788 (0.40%)	446,881	Ref	
Total		703,973 (99.56%)	3,146 (0.44%)	<b>707,119</b>		

#### 4.2.5.2 Health system enablers

Table 17 captures information regarding the discussion of ‘disease prevention’ and if women sought services related to disease prevention. Although this variable is not related to BC screening directly, it provides insights into the effect of health promotion. Women who had a discussion regarding disease prevention accessed related services 12.3 times higher than women who were not engaged in a discussion about disease prevention with health workers (2.91% vs. 0.24%,  $p < 0.001$ ).

*Table 17: Cross-tabulation of discussion regarding disease prevention and seeking of related services*

‘Disease prevention’ discussed 3 months prior to data collection	‘Disease prevention’ service sought in 3 months prior to data collection			
	No, n (%)	Yes, n (%)	Total, n	OR (95% CI), p value
<b>No</b>	586,638 (99.76%)	1,433 (0.24%)	588,071	Ref
<b>Yes</b>	10,688 (97.09%)	320 (2.91%)	11,008	12.26 (10.84-13.86), 0.00
<b>Total</b>	597,326 (99.71%)	1,753 (0.29%)	<b>599,079</b>	

*Pearson  $\chi^2(1) = 2.6e+03$ ;  $p = 0.000$*

CI, confidence interval; OR, odds ratio.

Media exposure and its association with BC screening are presented in Table 18. For the sake of bivariate analysis, responses to the frequency of exposure were modified – ‘less than once a week’ and ‘at least once a week’ were merged and recategorized as ‘yes’. Women who watched television were more likely to undergo BC screening than woman who read newspapers and magazines or listened to radio. All the associations were statistically significant.

Table 18: Cross-tabulation of media exposure and breast cancer screening uptake

Type of media exposure		Ever undergone breast examination			OR (95% CI), p value	Pearson chi2, p value
		No, n (%)	Yes, n (%)	Total, n		
Reading newspaper or magazine	Not at all	482,425 (99.60%)	1,951 (0.40%)	484,376	Ref	61.5842 Pr = 0.000
	Yes	221,548 (99.46%)	1,195 (0.54%)	222,743	1.33 (1.24-1.43), 0.00	
Listening to radio	Not at all	606,056 (99.58%)	2,551 (0.42%)	608,607	Ref	61.5842 Pr = 0.000
	Yes	97,917 (99.40%)	595 (0.60%)	98,512	1.44 (1.32-1.58), 0.00	
Watching television	Not at all	194,675 (99.70%)	586 (0.30%)	195,261	Ref	127.6799 Pr = 0.000
	Yes	509,298 (99.50%)	2,560 (0.50%)	511,858	1.67 (1.52-1.82), 0.00	
<b>Total</b>		703,973 (99.56%)	3,146 (0.44%)	<b>707,119</b>		

CI, confidence interval; OR, odds ratio.

#### 4.2.6 Multivariable analysis (Logistic regression)

The results of multivariable logistic regression models for assessing the associations between socio-demographic variables, personal and perceived health system barriers, and BC screening uptake are presented in Table 19. As mentioned earlier in the methodology, due to the unavailability of the complete data set for women's empowerment and health promotion-related variables, they were not part of the logistic regression model.

After adjusting for all variables, results indicate that the likelihood of undergoing BC screening increased with increasing age and education level. Women with higher education were twice as likely as uneducated women or women with primary education to undergo BC screening (AOR 2.10; 95% CI: 1.87-2.37).

Table 19: Logistic regression results for BC screening uptake in India, NFHS-5, N=707,119

Variables		AOR (95% CI)	p value	
Age	15-29	Ref		
	30-39	1.66 (1.50-1.83)	0.00	
	40-49	2.20 (1.99-2.44)	0.00	
Place of residence	Rural	Ref		
	Urban	1.37 (1.26-1.48)	0.00	
Region	Central	Ref		
	East	0.52 (0.44-0.62)	0.00	
	North	0.62 (0.53-0.73)	0.00	
	North-east	0.81 (0.69-0.95)	0.02	
	South	3.58 (3.22-3.96)	0.00	
	West	0.95 (0.83-1.09)	0.49	
Religion	Hindu	Ref		
	Muslim	0.78 (0.68-0.88)	0.00	
	Christian	1.44 (1.26-1.65)	0.00	
	Others	1.40 (1.15-1.70)	0.01	
Educational attainment	Primary/Nil	Ref		
	Secondary	1.67 (1.52-1.82)	0.00	
	Higher	2.10 (1.87-2.37)	0.00	
Marital status	Never married	Ref		
	Married	2.68 (2.32-3.08)	0.00	
	Widowed/ Divorced/ Separated	2.51 (2.05-3.08)	0.00	
Perceived personal barriers – getting medical help for self	Getting permission to go to health facility	Not a problem	0.98 (0.89-1.08)	0.67
		Is a problem	Ref	
	Getting money for health services	Not a problem	1.18 (1.08-1.30)	0.00
		Is a problem	Ref	
	Not wanting to go alone	Not a problem	0.80 (0.73-0.88)	0.00
		Is a problem	Ref	
Perceived health system barriers – getting medical help for self	Distance to health facility	Not a problem	1.13 (1.02-1.26)	0.03
		Is a problem	Ref	
	Needing transport to health facility	Not a problem	0.97 (0.87-1.08)	0.55
		Is a problem	Ref	
	Lack of HCPs	Not a problem	0.97 (0.86-1.08)	0.56
		Is a problem	Ref	
	Lack of female HCPs	Not a problem	0.99 (0.88-1.11)	0.84
		Is a problem	Ref	

AOR, adjusted odds ratio; CI, confidence intervals; HCP, healthcare professionals.

Geographic regions were seen to be an important indicator of BC screening uptake. The association with BC screening uptake was strongest in South Indian women as they had a higher chance to undergo BC screening than women from Central India (AOR 3.58; 95% CI:3.22-3.96). BC screening uptake varied by place of residence, with urban women having a higher likelihood of undergoing breast examination than rural women (AOR 1.37; 95% CI:1.26-1.48). The association between BC screening uptake and Christian women was the strongest as they had a higher chance to undergo BC screening than Hindu women (AOR 1.44; 95% CI:1.26-1.65). Married women had a greater probability of undergoing BC screening than unmarried women (AOR 2.68; 95% CI:2.32-3.08).

A positive association was observed between BC screening uptake and women not having financial constraints to access health services (AOR 1.18, 95% CI:1.08-1.30). Women who did not mind going alone to a health facility to 'get medical help for self' were less likely to undergo BC screening compared to women who did not want to go alone (AOR 0.80, 95% CI:0.73-0.88). This finding is contrary to the results from bivariate analysis and common understanding. On further analysis, when adjusted for women's age, marital status, and religion, results showed a positive association between BC screening uptake and women not having trouble going alone. However, when further adjusted for women's education, region, or residence location, results showed a negative association between BC screening uptake and women not having trouble going alone. This is indeed a complex variable that depends on women's preferences, perception of safety, social norms etc. There may be other variables influencing these results that need to be explored.

When adjusted for all variables, distance to health facilities was a significant health system barrier to BC screening uptake (AOR 1.13, 95% CI:1.02-1.26). However, getting permission to go to health facilities and other health system barriers such as lack of HCPs, lack of female HCPs, and needing transport to access health facilities were not significant barriers to BC screening uptake.

## 5. Discussion

The general objective of this study was to explore the associations of BC screening uptake in India focusing on the role of women's empowerment and health system factors. Only 0.44% of women aged 15 to 49 years in NFHS-5 data have ever undergone a breast examination, which is lesser than the BC screening uptake of 9.7% as per NFHS-4 done in 2015-2016.<sup>52</sup> The most influencing factors for BC screening uptake are age, education, women's autonomy, region - which to some extent dictates distance to facility, and health promotion activities.

BC is generally known as a disease of the older age group, and the national guidelines also suggest BC screening for women aged 30 years and above.<sup>10</sup> The present study showed that older women were more likely to undergo BC screening than younger women, which is consistent with another study on NFHS-5 data<sup>25</sup> but differs slightly from a study on NFHS-4 data that showed higher uptake in women aged 25 to 39 years.<sup>53</sup> The variation observed in the NFHS-4 study could be due to a higher possibility of women aged 25 to 39 years engaging with the health system for reproductive services, and thus potentially accessing opportunistic services such as BC screening. The overall positive association with age could be because the younger population seldom seek health services, and thus are not exposed to promotional messages and opportunistic services provided at health centers.

Geographically, there was a strong association with BC screening in South Indian women. South India consists of five states – Andhra Pradesh, Karnataka, Kerala, Tamil Nadu (TN), and Telangana, and three UTs – Andaman and Nicobar Islands, Lakshadweep Islands, and Puducherry ([Annexure 3](#)). Of these, BC screening uptake was highest in TN (3.94%), followed by Andaman and Nicobar Islands (3.50%), Puducherry (1.71%), and Kerala (1.56%). These four regions have the highest BC screening uptake even when compared with the rest of the country.

The high contribution from TN can be attributed to the Tamil Nadu Health Systems Project initiative by the Government of TN. Funded by the World Bank, this decade-old initiative aimed to provide opportunistic screening for cervical and breast cancers for women aged 30 and above.<sup>54</sup> The state of Kerala is known to be the best in utilizing public healthcare.<sup>55</sup> As part of a large-scale RCT in Kerala, which is one of the two BC screening-related RCTs in India, 50,000

women underwent CBE.<sup>56</sup> It is possible that the women who were part of the study were also part of NFHS-5, thus explaining the high BC screening uptake in Kerala. Puducherry has four small geographically unconnected districts within TN, Andhra Pradesh, and Kerala. This geographical overlap with TN and Kerala potentially explains the high BC screening numbers in Puducherry. In Andaman and Nicobar Islands, over 20,000 women have been screened as part of the NP-NCD,<sup>57</sup> which is a relatively high screening coverage of 9.3% in the UT and probably explains the high BC screening uptake seen in NFHS-5<sup>58</sup>. However, despite these state-specific programmes and large-scale studies collectively contributing to South India's high BC screening uptake, the BC screening uptake rates are still very low. This indicates that while plans, policies, and strategies maybe in place, implementation challenges do exist.

A major proportion of India's population resides in rural areas. Yet, as compared to urban India, rural India has disproportionately lesser healthcare infrastructure, translating to reduced access to services.<sup>59</sup> This inequity explains the negative association found in the study where BC screening was significantly lower in rural women than in urban women. On further analysis of the data, it was found that 66.23% of rural women found distance to a health facility a challenge than 42.94% of urban women ([Annexure 4](#)). Most rural women found it more problematic than urban women to take transport to reach the health facility. Rural women also shared concern about the lack of HCPs, specifically female HCPs, more than urban women. ([Annexure 4](#)) These concerns were also shared in other studies done in India.<sup>25,35,36,41,46</sup>

Women who identified themselves as Christians were 1.4 times more likely to get screened for BC than women of other religions as per the analysis in this study. This was consistent with results from analysis of NFHS-4 data, where the coverage was high among wealthier Christians.<sup>46</sup> However, in an RCT in Kerala, where among screen-positive women, Hindus were 40% more likely to attend breast clinics than Christians.<sup>60</sup> As these varied results do not bring clarity to the role of religion in BC screening, the interplay of SES and religion could be explored in future studies.

BC screening uptake was positively associated with higher education in the study. This was consistent with findings from other studies as well.<sup>25,46</sup> However, being educated is not the same as being cancer aware,<sup>44</sup> as lack of cancer awareness in both the general population and HCPs,

was probably the single most prominent barrier that was seen in multiple studies across India.<sup>28-42</sup> The lack of cancer awareness, even among the educated, probably reflects the social stigma and taboo surrounding the disease, hindering open communication among people, including BC patients. In this study, lack of cancer awareness was not quantitatively evaluated as it was not part of NFHS-5 questionnaire.

Married women were more likely to go for BC screening than unmarried women. This positive association between marital status and BC screening uptake was initially attributed to age, but the association remained positive even after adjusting for age in the logistic regression analysis. Earlier analyses of NFHS-4 and NFHS-5 data have also shown an association between married women and BC screening uptake.<sup>25,46</sup> Marriage and partnership have been positively associated with mammography uptake in Switzerland.<sup>50</sup> This protective effect of marital partners, however, should be analyzed within a socio-cultural context and through the gender lens. Further studies could also explore the possible influence of financial stability within marriages on women's health seeking behavior.

In the study, women's autonomy over their earnings, healthcare, or movement was associated with high BC screening uptake. This finding is consistent with previous studies done in India, Bangladesh and Ethiopia.<sup>26,61,62</sup> However, a study on NFHS-5 data revealed that this correlation was not uniform across all Indian states,<sup>26</sup> probably due to India's highly diverse demography and geography. Although not significant, over 70% of the women made these decisions along with their husbands/partners and were more likely to access BC screening services than women who were not part of the decision-making process at all in the study. However, due to the cultural context, these variables probably are not the most appropriate means of measuring women's empowerment. It could be that in the patriarchal society of India, men are generally older than their wives/partners, are heads of households, and most often are the only earning members of the family, possibly making them the default decision-makers culturally. Studies conducted in 'developing countries' argue that decisions made jointly with husband/partner may not necessarily mean lower autonomy.<sup>63,64</sup> In fact, intra-spousal communication on matters of health and finances is probably a sign of healthier communication as they demonstrate mutual support



and interdependent roles in a household. Qualitative studies can help better understand the nuances of women's autonomy and derive other variables to describe women's autonomy in relation to healthcare decisions, not limiting to reproductive health alone.

Getting permission to go to a health facility was problematic for more than one-third of the respondents. About 40% of the respondents did not want to go to a health facility alone, which is consistent with results from qualitative studies<sup>37,39</sup>. These two variables can be observed from a culture's perspective. For the sake of safety, women in India are not allowed to go 'alone' outdoors. Venturing out alone could attract shaming and stigma. As a result, not allowing women to go out alone has probably been normalized culturally and is evident in households, hostels of educational institutions, peer groups, and workplaces.<sup>65</sup> Men being primary earners may not be able to take leave from work often to accompany women to a health facility, limiting her access to healthcare. As a patriarchal society, most Indian husbands expect their wives to seek permission to go out of the house.<sup>52</sup> This inherently gendered discipline is deep-rooted culturally for centuries, and hence can only be addressed through an inter-sectoral approach of creating awareness in both men and women, providing equal education and work opportunities for women, making society safe and women-friendly, improving infrastructure related to transport and healthcare facilities, providing women with financial security, and so on.

Distance to health facility was a significant barrier for women to access BC screening services, and was seen in other studies as well.<sup>29,30,33,34,36,37,39,45</sup> Concerns about transport to a health facility, HCP availability, and no female HCPs were associated with reduced BC screening, although not significant when adjusted for other variables. Lack of healthcare workforce, especially that of female HCPs, is a recurring barrier in many studies.<sup>29,30,34,36,37,39</sup> This association between health system barriers and BC screening uptake can be attributed to the rural-urban disparity in India's health system.<sup>59</sup> Increasing the number of female doctors and specialists is a time-sensitive approach. Instead, a more effective approach to having a culture-appropriate workforce would be to encourage task-shifting by training women from the community for promoting health and delivering basic healthcare services. Such trained female community workers can bridge the gap by performing outreach activities to ensure that travel impediments,

especially in rural communities, do not aggravate health system barriers. This local capacity building can go a long way in strengthening the health system.

The literature review conducted for this study highlights increasing awareness about cancer, cancer screening, and available healthcare facilities as enablers for increasing BC screening uptake.<sup>32–35,41,44</sup> In this study, women who were exposed to the concept of disease prevention by health workers were 12.3 times more likely to access related services than women who were not engaged in a discussion about disease prevention with health workers. House or field visits by health workers are usually the first link between the health system and the communities, and hence, are instrumental in health promotional activities. Generally, the health workers are from the community and hence, there could be a relationship of trust that is built probably explaining the high impact.

Although beyond the scope of this study, it is crucial to note that among the 19.70% of respondents who met an ANM/LHV in the last 3 months, disease prevention was discussed with only 6.47% of them; and among the 28.39% of respondents who met an Anganwadi worker/ASHA/CHW in the last 3 months, disease prevention was discussed with only 8.26% of them ([Annexure 5](#)). This demonstrates a gap in effective outreach activities. However, it remains to be seen if the barriers to these outreach and promotional activities are similar to the barriers affecting BC screening uptake.

Newer BC screening technologies are gaining traction in India. Key advantages of these digital technologies are that they can be scaled up as they are not infrastructure-intensive and can be used by low-skilled health workers.<sup>66,67</sup> As a step forward, these technologies can be used to provide service at the point of first contact between health workers and the community. Training female healthcare workers on such technologies can help in three ways – increasing effective coverage by taking healthcare services to the households, task shifting and thus reducing the work burden on doctors and nurses, and providing a means of employment and financial stability to women.

Media channels like newspapers, magazines, radio, and television are also means of disseminating information and thus, increasing health awareness. However, as literacy rates are low in rural areas, in elderly women aged between 40 and 49 years, and those in the lowest wealth quintile,<sup>22</sup> using newspapers and magazines for health promotion activities may not be very effective. This was also observed in a qualitative study where many women were not inclined to read newspapers and hence preferred other sources of information.<sup>35</sup> Although listening to the radio is significantly associated with BC screening uptake, it may not be the best medium for disseminating information as the popularity of radio is lowest (13.93%) in both urban and rural India compared to print medium and visual mediums ([Annexure 6](#)).

Visual medium, such as television, is popular, probably due to the soap operas. But not everyone in India can afford to have a television at home. Alternate visual mediums, such as health information painted on walls of houses, compounds, and health centers, are commonly used to create awareness in India (Image 1). Further studies exploring the cost-effectiveness of this comparatively simple visual medium for health promotion can be considered.



*Image 1: Using walls as a medium to spread awareness about nutrition during pregnancy in India. Image source: Outlook India<sup>68</sup>*

## Study limitations

The NFHS-5 data is collected for reproductive health outcomes and contains data of women in the reproductive age of 15 to 49 years. Therefore, women aged 50 years and above are not represented. Additionally, the variables used for data collection mainly serve as indicators for reproductive health. Hence, the reliability and validity of the data used for this study might not apply explicitly to BC screening uptake. For example, a pregnant lady or young mother may want to be accompanied to a health facility, for both physical and emotional reasons. So, when women said that they did not want to go alone to a health facility, they could have responded bearing in mind the experience of pregnancy and motherhood.

There could be other relevant factors influencing BC screening behaviors among Indian women that were not included in the NFHS questionnaire. For example, the literature review showed that a family member's BC may be a motivating factor to seek BC screening services. However, the NFHS questionnaire did not have a provision to collect this information.

Variables such as 'getting medical help for self' elicit subjective responses and may suffer from bias, including interviewer-induced bias. Women's empowerment variables had limited data due to sampling methods and hence, could not be used for multivariable analysis. There is a possibility that not all potential confounding variables, particularly SES, were controlled for in the analysis and this might have affected the overall results.

Rural women formed three-fourths of the study population. Hence, a rural vs. urban sub-group analysis for all the variables evaluated in this study would have probably provided depth to the analysis. Future research evaluating such a sub-group analysis may provide more definite answers regarding factors influencing BC uptake.

## 6. Conclusion and Recommendations

As a step towards achieving UHC, the Indian government is revamping its existing primary care services to provide free comprehensive primary healthcare, which includes BC screening as well. As per the latest NFHS-5 data, the overall BC screening uptake was just 0.44% indicating a very low screening uptake in a country where over 90,000 women succumb to the disease every year. As the incidence and mortality rate of BC continues to rise in India, it is crucial and urgent to identify the factors influencing women's participation in the BC screening program to customize targeted approaches that will effectively increase their participation.

This study aimed to explore the associations of BC screening uptake in women aged 15 to 49 years, with a focus on women's empowerment and health system factors. Despite the socio-cultural and geographic diversity within the country, common barriers and enablers emerged from the analysis of the NFHS-5 dataset of 709,119 Indian women. The most prominent predictor variables influencing BC screening uptake were age, education, region, and health system factors such as distance to health facilities and health promotion activities. Women's empowerment was positively associated with BC screening but requires further research to accurately quantify the association.

Older, educated, urban women were more likely to undergo BC screening. As compared to younger women, older women perceive health issues as concerning and hence seek relevant services more actively. Education was positively associated with screening uptake, although it cannot be directly linked with cancer awareness. Lack of cancer awareness is prevalent among both the general population and healthcare providers, reflecting the need for nation- and state-wide awareness programmes to improve cancer awareness and reduce the social stigma and taboo surrounding the disease. Religion seemed to play a role as more Christian women underwent BC screening in a country that has a majority Hindu population. Marital status also played a role in BC screening uptake, with married women being more likely to undergo screening compared to unmarried women. Religion and marriage may have many confounding factors that need to be explored within socio-cultural and socio-economical contexts to better understand their influence on BC screening uptake.

The location of residence had a major impact on BC screening uptake. Rural India exhibited significantly lower BC screening rates than urban areas, primarily due to inequitable healthcare infrastructure and reduced access to services. South India had the highest BC screening rates in the country. While this high rate can be attributed to state-specific initiatives and studies, the BC screening rates are still abysmally low at less than 5%. It remains to be explored if the challenges lie in the implementation of these initiatives or the establishment of initiatives themselves. This information would be useful for other state governments wanting to replicate the initiatives' success, however minimal, in their states. It would be valuable to further explore the influence of rural-urban differences within South India and other regions in the country.

Women's empowerment, assessed as women's autonomy over their earnings, healthcare, and movement, positively affected screening uptake. However, women's empowerment is a layered, complex issue that may not have been fully captured in the NFHS data. Gender, culture, education, SES, region, and religion are just a few factors that play a role in women's empowerment. Conducting qualitative studies is essential to determine appropriate parameters for evaluating women's empowerment accurately.

Distance to a health facility stands as a barrier, alongside other health system factors like the requirement for transport to reach health facilities and the scarcity of HCPs, particularly female HCPs. The latter three factors did not show statistical significance when adjusted for other variables in BC screening uptake. The lack of female HCPs is a cultural issue and needs to be addressed to make healthcare services accessible. It may take enormous time to increase the number of female nurses, doctors, and specialists. Hence, a more effective approach is to engage the community and train women from the local community for the delivery of basic healthcare services. Such task-shifting strategies bridge gaps in the health workforce, one of the six building blocks in WHO's framework for health systems strengthening.

All the health system factors play a role in rural communities where healthcare infrastructure and workforce are disproportionately distributed to their disadvantage. In such rural settings, field visits by trained community healthcare workers become important in bridging the rural-urban gap and ensuring equitable access to healthcare for women. Health promotion activities

was a distinctive enabler and had a substantial impact on accessing preventive services, emphasizing the importance of increasing awareness in the community. Visual mediums, such as painted visuals on walls and television have the potential to increase awareness for BC screening. Including health promotion activities in popular soap operas on television as part of the series and not as separate advertisements could be more influential on women.

In a resource-constrained country like India, health infrastructure is not always accessible, the workforce is sometimes unavailable, and service delivery is unregulated. In such settings, innovation-led, technology-assisted solutions have the potential to scale up services with affordability, improve accessibility, and enhance the quality of healthcare. Training women from the community on using newer technologies can increase BC screening uptake during house and field visits.

Limited cancer literacy in both the general population and HCPs, limited women's autonomy along with health system-related factors such as limited access to healthcare infrastructure, services, and professionals are contributing factors to reduced BC screening uptake. The study highlights the need for targeted interventions addressing social determinants of health such as education, cultural norms, healthcare accessibility, and women's empowerment to improve BC screening uptake in India. Based on the findings of this study, I would like to recommend the following interventions:

A) To policymakers and strategists at the national level (MoHFW, GoI)

1. Implement policies that promote gender equity in healthcare and address cultural barriers. Engage with multiple stakeholders for an intersectoral approach to empower women through education and financial security, especially in rural areas, to ensure timely access and appropriate medical care.
2. Invest in health promotional activities to increase nationwide cancer awareness among all household members and to bust myths and misconceptions. Disseminate information through visual media like painting walls and use influencers on television channels to make the messaging relatable and impactful.

3. Evaluate existing programmes that have contributed to increased BC screening uptake in South India. This will be useful to understand the strengths and limitations of these programmes and apply that knowledge while designing programmes for other regions of India. The findings will also be useful to inform strategies for other health programmes beyond BC screening.
  4. Expand telemedicine and digital/mobile technology for health initiatives to bring healthcare services closer to remote communities.
- B) To strategists and implementors at [State](#) Government level
1. Build capacity of female healthcare workers from the local communities and train them in health promotional activities. Also, train them in the delivery of low-skilled basic healthcare services, including the use of novel technology innovations to encourage task-shifting and increase coverage of health services. Capacity building serves the dual purpose of achieving health outcomes while empowering women.
  2. Invest in more community-based healthcare programs to provide outreach and support to underserved populations. The trained female healthcare workers from local communities are the sound foundation to ensure the success of such community-based healthcare programmes.
  3. Invest in transportation infrastructure and improve travel networks to enhance healthcare accessibility. This can go a long way in ensuring that all individuals can access services promptly and improve overall socio-economic development.
- C) To research organizations and researchers
1. Conduct surveys to obtain national-level data regarding BC screening uptake and the factors affecting it for women aged 50 to 65 years. These surveys can be extended to include similar information on other cancers too. Additionally, in the next round of NFHS data collection, obtain reasons for not undergoing cancer screening and information about relevant risk factors such as the family history of BC. As most NCDs share common risk factors, such information will be useful for



planning health promotional activities and strategizing NCD screening programmes, including BC cancer.

2. Perform qualitative analysis for determining appropriate variables to assess women's empowerment that has an impact on BC screening uptake.
3. Perform validation studies of medical technology innovations in community outreach programmes to evaluate its feasibility and cost-effectiveness in real-world settings.

Intra-sectoral approach and multi-stakeholder engagement to involve the community, disseminate information, empower women, improve healthcare access and quality, and use of technological advancements are essential to bridge the gap in cancer awareness and utilization of healthcare services. Such multi-dimensional efforts will lead to a reduced burden of BC in the country. However, BC screening cannot happen in isolation and should be a part of larger health initiatives for both communicable and non-communicable diseases. The strategies recommended above are aligned with the interests of NP-NCD ensuring overall improved health outcomes and progress toward achieving UHC. Furthermore, these strategies will also promote overall well-being and socio-economic development and are steps towards the fulfillment of sustainable development goals.

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## 8. Annexures

Annexure 1: List of variables from NFHS-5 data that have been studied for association with BC screening uptake<sup>25,26</sup>

<b>Demographics</b>	<b>Socio-economic Status</b>	<b>Women's Empowerment</b>
Age	Presence of electricity	Literacy and education level in women
Marital status	Drinking water source (improved)	Participation of women in decisions regarding healthcare for self
Religion	Sanitation facility (improved)	Participation of women in making major household purchases
Social group	Using clean fuel for cooking	Participation of women in decisions regarding visits to her family and relatives
Place of residence, region	Consumer durables (presence of car, refrigerator, television, mobile etc)	Women working for the past 12 months and were paid in cash
Health insurance	Sex of household head	Women owning a house or land alone or with a husband
Use of hormonal contraception	Materials used for house construction	Women who have a bank or savings account that they operate themselves
Body-mass index (BMI)		Women having a mobile phone that they use themselves
Drinking habits, tobacco consumption, eating habits (eat fried food, fruits)		Women who use hygienic protection methods during their menstrual period
		Media exposure

Annexure 2: List of keywords used for literature search

<b>Problem</b>	<b>AND</b>	<b>Factor</b>	<b>AND</b>	<b>Geography</b>
Breast Cancer		Barriers		India
Carcinoma Breast		Enablers		LMIC
		Mammography		South India
		CBE		North India
		BSE		North-east India
		Personal barriers		West India
		Women's empowerment		East India
		Women's autonomy		Central India
		Socio-economic barriers		
		Cultural barriers		
		Health system barriers		
		Health promotion		
		Cancer literacy		
		Cancer awareness		
		Religion		
		Screening programmes		
		Urban		
		Rural		
		Education		

Annexure 3: Categorization of Indian states by geographical region and cross-tabulation of regions with breast cancer screening uptake

Central Indian States and UTs	Ever undergone breast examination		
	No	Yes	Total
Chhattisgarh	27,813	50	27,863
	99.82%	0.18%	100%
Madhya Pradesh	46,401	189	46,590
	99.59%	0.41%	100%
Uttar Pradesh	90,232	264	90,496
	99.71%	0.29%	100%
<b>Total</b>	164,446	503	164,949
North Indian States and UTs	Ever undergone breast examination		
	No	Yes	Total
Haryana	21,148	56	21,204
	99.74%	0.26%	100%
Himachal Pradesh	10,230	28	10,258
	99.73%	0.27%	100%
Jammu & Kashmir	22,477	51	22,528
	99.77%	0.23%	100%
Punjab	20,654	54	20,708
	99.74%	0.26%	100%
Uttarakhand	12,801	19	12,820
	99.85%	0.15%	100%
Chandigarh (UT)	670	0	670
	100%	0%	100%
Ladakh (UT)	2,310	4	2,314
	99.83%	0.17%	100%
NCT of Delhi (UT)	10,512	26	10,538
	99.75%	0.25%	100%
<b>Total</b>	100,802	238	101,040
East Indian States and UTs	Ever undergone breast examination		
	No	Yes	Total
Bihar	41,444	87	41,531
	99.79%	0.21%	100%
Jharkhand	25,957	38	25,995
	99.85%	0.15%	100%
Odisha	27,615	34	27,649
	99.88%	0.12%	100%
West Bengal	21,061	28	21,089
	99.87%	0.13%	100%
<b>Total</b>	116,077	187	116,264
North-East Indian States and UTs	Ever undergone breast examination		
	No	Yes	Total
Arunachal Pradesh	19,542	64	19,606
	99.67%	0.33%	100%
Assam	34,511	54	34,565
	99.84%	0.16%	100%
Manipur	7,934	60	7,994
	99.25%	0.75%	100%
Meghalaya	12,948	20	12,968
	99.85%	0.15%	100%
Mizoram	7,119	81	7,200
	98.88%	1.12%	100%
Nagaland	9,637	24	9,661
	99.75%	0.25%	100%
Tripura	7,207	16	7,223
	99.78%	0.22%	100%
Sikkim	3,206	4	3,210
	99.88%	0.12%	100%
<b>Total</b>	102,104	323	102,427

UT, union territories

Annexure 3: Categorization of Indian states by geographical region and cross-tabulation of regions with breast cancer screening uptake (*cont.*)

South Indian States and UTs	Ever undergone breast examination		
	No	Yes	Total
Andhra Pradesh	10,669	63	10,732
	99.41%	0.59%	100%
Karnataka	29,570	58	29,628
	99.8%	0.2%	100%
Kerala	10,563	167	10,730
	98.44%	1.56%	100%
Tamil Nadu	24,117	990	25,107
	96.06%	3.94%	100%
Telangana	26,356	87	26,443
	99.67%	0.33%	100%
Andaman & Nicobar Island (UT)	2,289	83	2,372
	96.5%	3.5%	100%
Lakshadweep (UT)	1,210	5	1,215
	99.59%	0.41%	100%
Puducherry (UT)	3,566	62	3,628
	98.29%	1.71%	100%
<b>Total</b>	<b>108,340</b>	<b>1515</b>	<b>109,855</b>
West Indian States and UTs	Ever undergone breast examination		
	No	Yes	Total
Gujarat	32,828	45	32,873
	99.86%	0.14%	100%
Goa	1,982	18	2,000
	99.1%	0.9%	100%
Maharashtra	32,535	262	32,797
	99.2%	0.8%	100%
Rajasthan	42,211	52	42,263
	99.88%	0.12%	100%
Dadra & Nagar Haveli (UT)	2,648	3	2,651
	99.89%	0.11%	100%
<b>Total</b>	<b>112,204</b>	<b>380</b>	<b>112,584</b>

UT, union territories

Annexure 4: Cross-tabulation of perceived health system factors with type of residence

Getting medical help for self		Type of residence		Pearson chi2(1), p value
		Urban (n,%)	Rural (n,%)	
Distance to health facility	Not a problem	98,809 (57.06%)	180,333 (33.77%)	3.0e+04 p = 0.000
	Is a problem	74,362 (42.94%)	353,615 (66.23%)	
Having to take transport to health facility	Not a problem	102,883 (59.41%)	189,446 (35.48%)	3.1e+04 p = 0.000
	Is a problem	70,288 (40.59%)	344,502 (64.52%)	
Concern of no healthcare provider	Not a problem	73,592 (42.50%)	150,985 (28.28%)	1.2e+04 p = 0.000
	Is a problem	99,579 (57.50%)	382,963 (71.72%)	
Concern of no female healthcare provider	Not a problem	82,134 (47.43%)	178,104 (33.36%)	1.1e+04 p = 0.000
	Is a problem	91,037 (52.57%)	355,844 (66.64%)	
Total		173,171	533,948	

Annexure 5: Cross-tabulation of contact with health worker and discussion of disease prevention

Respondent met with health worker in last 3 months		'Disease prevention' discussed 3 months prior to data collection			
		No, n (%)	Yes, n (%)	Total, n	Pearson chi2, p value
<b>ANM/LHV</b>	No	559,258 (98.49%)	8,583 (1.51%)	567,841	1.1e+04 p = 0.000
	Yes	130,254 (93.53%)	9,014 (6.47%)	139,268	
<b>Anganwadi worker/ ASHA/CHW</b>	No	505,334 (99.80%)	1,015 (0.20%)	506,349	3.8e+04 p = 0.000
	Yes	184,178 (91.74%)	16,582 (8.26%)	200,760	
<b>Total</b>		<b>689,512</b>	<b>17,597</b>	<b>707,109</b>	

ANM, Auxiliary Nurse Midwives; ASHA, Accredited Social Health Activist; CHW, community health worker; LHV, Lady Health Visitor

Annexure 6: Cross-tabulation of media exposure with type of residence

Type of media exposure		Urban	Rural	Pearson chi2(1), p value
Reading newspaper or magazine	Not at all	89,423 (18.46%)	394,953 (81.54%)	3.0e+04 p = 0.000
	Yes	83,748 (37.60%)	138,995 (61.40%)	
Listening to radio	Not at all	143,320 (23.55%)	465,287 (76.45%)	2.1e+03 p = 0.000
	Yes	29,851 (30.30%)	68,661 (69.70%)	
Watching television	Not at all	21,972 (11.25%)	173,289 (88.75%)	2.6e+04 p = 0.000
	Yes	151,199 (29.54%)	360,659 (70.46%)	