

Learning from the Indian National Family Health Survey to assess population based oral, cervix and breast cancer screening in low-and-middle income countries

Kakoli Borkotoky,^a Lucky Singh,^b Prashant Kumar Singh,^{a,*} and Shalini Singh^a

^aICMR–National Institute of Cancer Prevention and Research (NICPR), Indian Council of Medical Research (ICMR), Noida, Uttar Pradesh, India

^bIndian Council of Medical Research (ICMR), New Delhi, India

In 2020, approximately 19.3 million new cancer cases and 10 million cancer deaths were reported worldwide.¹ In the coming decades, low- and middle-income countries (LMICs) will contribute the most to the global cancer burden in terms of both incidence and deaths.² Compared to developed countries, comprehensive data on population-level cancer screening is lacking in LMICs, posing a profound challenge to effectively manage the growing burden of cancer.³ This report aims to consolidate the learnings from the population-level cancer screening data from India, collected in the Demographic and Health Surveys (DHS). The observations shared here can be utilized in countries where DHS is routinely conducted to assess cancer screening coverage.

Since 1984, the DHS has been a great source of high-quality data on crucial population health and wellbeing indicators in over 90 LMICs.⁴ In India the DHS survey is known as the National Family Health Survey (NFHS). The first round of NFHS was conducted in 1992–93 and till date five rounds have been completed successfully. The NFHS study tool is updated with each successive round to provide data on emerging health issues and indicators of global and national importance.⁵

Questions on cervix, breast, and oral cavity examination were introduced in NFHS-4 (2015–16). The question was, “Have you ever undergone a cervix/breast/oral cavity examination?” Out of 699,686 women interviewed, only 22%, 10%, and 12% of women (aged 15–49) reported undergoing cervix, breast, or oral cavity examinations, respectively.³ These questions were also asked in NFHS-5 (2019–21) with some modifications. The questions for NFHS-5 were rephrased as, “Have you ever undergone a screening test for cervical cancer?”, “Have you ever undergone a breast examination for breast cancer?”, and “Have you ever undergone an oral cavity examination for oral cancer?” Only 1.2% (cervical), 0.6% (breast), and 0.7% (oral) out of the

765,805 women interviewed during NFHS-5 confirmed undergoing cancer screening.⁶ The proportion of men reporting oral cavity examinations was 9% (out of 112,122 interviewed men) in NFHS-4, which reduced to 0.2% (out of 716,443 interviewed men) in NFHS-5.

The unexpected decline from NFHS-4 to NFHS-5 requires detailed investigation into the possible reasons. The Indian Council of Medical Research report from the cancer registry program (2020) projected that the cancer burden in India will increase from 1.39 million in 2020 to 1.57 million in 2025.⁷ If we consider that the awareness for the three types of cancers (cervix, breast, and oral) have increased over time, then the percentage of respondents who had undergone screening should not have drastically dropped between NFHS-4 and NFHS-5. The drop may be due to other factors that influenced the responses. Possible reasons for the decline could include changes in the reference period to measure screening, changes in the survey implementation process, or modifications in the framing of the questions between the consecutive rounds.

In both NFHS-4 and NFHS-5, the question on cervical and breast examinations was asked referring to “ever undergone screening...,” so we may assume that the reference period did not influence the responses. Additionally, in NFHS-4, the question did not include any reference to the terms “screening” or “cancer.” More than 75% of women interviewed in NFHS are “ever-married” and have had children. There is a possibility that some women confused a regular pelvic examination during pregnancy as screening for cervical cancer, leading to overestimation of cancer screening in NFHS-4.⁸ However, in NFHS-5, the question clearly mentions “screening for cancer,” which ensure that the response indicates screening specifically for these cancers. To check the response from the eligible population for cervical and breast cancer, we examined the screening percentage for women age 30–45 from NFHS. The responses clearly show a sharp decline in the proportion of women reporting cervix and breast examination (screening) from NFHS-4 to NFHS-5 across all age groups and education category (Fig. 1).

In terms of survey implementation, the only difference between NFHS-4 and NFHS-5 is that the questions related to breast, cervix, and oral cavity examinations were part of



The Lancet Regional Health - Southeast Asia 2024;30: 100483

Published Online xxx
<https://doi.org/10.1016/j.lansea.2024.100483>

*Corresponding author. Division of Preventive Oncology & Population Health, ICMR–National Institute of Cancer Prevention and Research, Noida, Uttar Pradesh, India.

E-mail addresses: prashants.geo@gmail.com, ks.prashant@icmr.gov.in (P.K. Singh).

© 2024 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

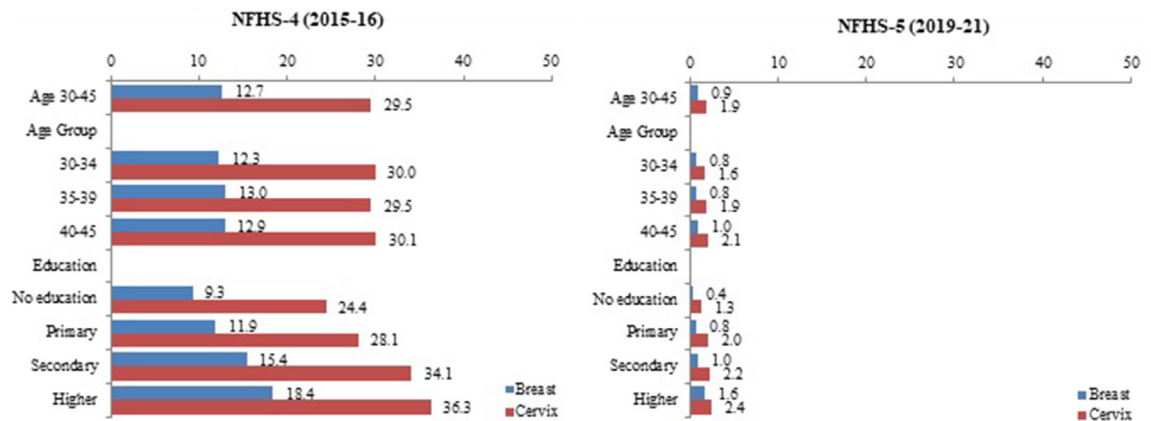


Fig. 1: Percentage of women age 30–45 reporting breast & cervix examination in NFHS-4 (2015–16) and in NFHS-5 (2019–21).

the individual questionnaire in NFHS-4, while in NFHS-5, questions related to cancer screening were part of the biomarker questionnaire. Therefore, we can rule out the role of survey implementation on low response to cancer screening question. The changes in the framing of the questions emerge as the only possible reason for the decline in response to having undergone screening percentages.

It is important to note that the questions used to report cancer screening in both NFHS-4 and NFHS-5 do not specify whether the examination was done in symptomatic women, as a regular check-up, or to detect suspected cancer. Thus, the screening percentages obtained from NFHS include both symptomatic women who underwent examination and asymptomatic women who had undergone cancer screening. Additionally, since the term ‘cancer’ is not mentioned in NFHS-4 questions, the estimates from NFHS-4 should not be used to report cancer screening percentages for India. Therefore, anyone using NFHS figures to quote cancer screening percentages in India should acknowledge that the figures are not comparable between NFHS-4 and NFHS-5 and the numbers include both symptomatic and asymptomatic women and men (for oral cancer). Moreover, NFHS-4 figures do not represent the baseline assessment of the cancer screening status in the country.

Future surveys should include a core set of questions on awareness (e.g., “Have you heard of breast/cervical/oral cancer?”) and screening (e.g., “Have you ever undergone test for cancer screening?”).^{9,10} Additionally, a follow-up question to identify whether women underwent screening as a routine procedure or because of being symptomatic would present a complete picture of cancer screening coverage and the effectiveness of government schemes to raise awareness and facilitate early detection. To conclude, the Indian experience of assessing population-based cancer screening using DHS (NFHS) suggest that countries aiming to use DHS for evaluating national coverage of cancer screening should ensure consistency in the questions to assess

long-term trends. This approach will help define appropriate strategies for the early detection of preventable cancers, ultimately reducing the burden of these cancers among the LMICs.

Contributors

PKS & LS conceptualized the study. LS & KB analyzed the data KB & PKS wrote the first draft. LS & SS conducted critical revisions. KB, LS, PKS & SS contributed to writing and approved the final manuscript.

Data sharing statement

This study used publicly available datasets. The DHS datasets can be availed from the DHS website (<https://dhsprogram.com/data/>) at the request of the registered users.

Declaration of interests

All the authors declare that they have no conflict of interest.

References

- Sung H, Ferlay J, Siegel RL, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2021;71(3):209–249.
- Pramesh CS, Badwe RA, Bhoo-Pathy N, et al. Priorities for cancer research in low-and middle-income countries: a global perspective. *Nat Med.* 2022;28(4):649–657.
- Goss PE, Strasser-Weippl K, Lee-Bychkovsky BL, et al. Challenges to effective cancer control in China, India, and Russia. *Lancet Oncol.* 2014;15(5):489–538.
- Corsi D, Neuman M, Finlay J, Subramanian S. Demographic and health surveys: a profile. *Int J Epidemiol.* 2012;41:1602–1613.
- IIPS. National Family Health Survey-4. *India fact sheet 2015-16.* 2017.
- (IIPS) II for PS, ICF. *National family health survey (NFHS-5), 2019-2021.* Mumbai; 2021. Available from: <https://dhsprogram.com/pubs/pdf/FR375/FR375.pdf>.
- Mathur P, Sathishkumar K, Chaturvedi M, et al. Cancer statistics, 2020: report from national cancer registry programme, India. *JCO Glob Oncol.* 2020;6:1063–1075.
- Van Dyne EA. Establishing baseline cervical cancer screening coverage—India, 2015–2016. *MMWR Morb Mortal Wkly Rep.* 2019; 68:14–19.
- Viens L, Perin D, Senkomago V, Neri A, Saraiya M. Questions about cervical and breast cancer screening knowledge, practice, and outcomes: a review of demographic and health surveys. *J Womens Health.* 2017;26(5):403–412.
- Nnaji CA, Moodley J. Collection of cancer-specific data in population-based surveys in low-and middle-income countries: a review of the demographic and health surveys. *PLOS Glob Public Heal.* 2023;3(9):e0002332.