POLICY BRIEF: Labels, language and other strategies to improve communication about ductal carcinoma in situ (DCIS) of the breast

PROBLEM

Due to widespread cancer screening, many people are diagnosed with "low-risk" lesions that may never transform into invasive cancer. One such example is ductal carcinoma in situ (DCIS), which accounts for 15% to 25% of screen-detected breast lesions. About 20% of women with DCIS develop invasive breast cancer. Until trials show that active surveillance is an effective way to manage DCIS, all women diagnosed with DCIS undergo surgery and/or adjuvant therapy. In prior research, women with DCIS and physicians reported challenges in communicating about low-risk forms of DCIS.

NEED

Many women with low-risk forms of DCIS are confused about whether they have cancer and why they need treatment. This causes anxiety that can persist many years after treatment, leading to poor physical and psychological outcomes, and reduced quality of life. Physicians also reported difficulty in explaining low-risk forms of DCIS and in justifying treatment, with many physicians referring to it as cancer.

STRATEGY

A panel of women who had DCIS and physicians from across Canada recommended the following ways to improve communication about low-risk forms of DCIS:

Category	Recommendations
Label other than DCIS	– While physicians preferred labels that referred to cancer (e.g. pre-cancer, stage 0 cancer), women preferred that physicians refer to "abnormal cells", particularly when first diagnosed
Language to explain DCIS	– Use plain/lay language that patients will understand – Explicitly state that DCIS is not invasive breast cancer – Explain the risk of spread and recurrence
Strategies to help explain DCIS	– Involve interpreters for women with English as a second language – Provide women with, or refer them to print or online resources about DCIS – Develop resources for women that are DCIS specific (i.e. not included in resources about invasive breast cancer) and culturally-tailored to various ethno-cultural groups – Use visual aids (pictures, models) – Ask women to articulate concerns or questions – Connect women with services or groups for more information and support – While physicians did not agree, women recommended: o Schedule longer physician visits to accommodate concerns/questions o Arrange follow-up visits soon after the diagnostic visit to address lingering concerns/concerns
Promoting use of these results	– Incorporate into existing breast cancer public awareness campaigns – Share with women via support services or groups and advocacy agencies – Share with physicians via professional societies and continuing education

ANALYSIS

A panel of 17 women who had DCIS and 20 healthcare professionals from across Canada were surveyed to rate DCIS labels, language and other strategies that had been generated through prior research. We retained items if ≥ 80% of panelists agreed on their importance.

Panelist characteristics

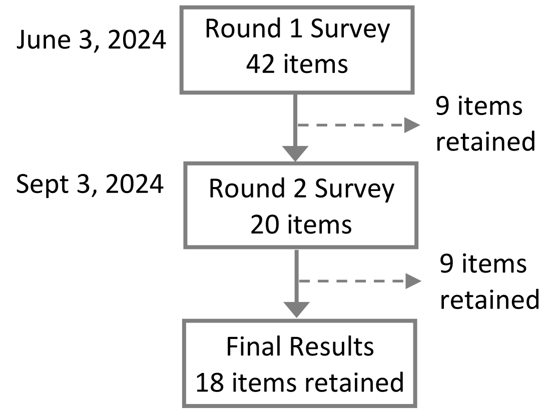
Women who had DCIS (n=17)

Race	n (%)
White	10 (58.8)
Non-white (Middle Eastern, South Asian, East Asian, Black)	7 (41.2)
Age (years)	**n (%)**
≤50	6 (35.3)
51-64	10 (58.8)
≥65	1 (5.9)

Healthcare Professionals (n=20)

Specialty	n (%)
Surgical Oncology	7 (35.0)
Radiation Oncology	4 (20.0)
Family Physician	3 (15.0)
Pathologist	2 (10.0)
Medical Oncology	1 (5.0)
General Surgeon	1 (5.0)
Screening Manager	1 (5.0)
Researcher/Scientist	1 (5.0)

Survey item rating results



1. Lyons MS, Dhakal S, Baker C, Chaput G, Finelli A, Kupets R, Look Hong NJ, Gagliardi AR. Preferred labels and language to discuss low-risk lesions that may be cancer precursors: A review. Patient Education and Counseling 2024;126:108321.
2. Lyons MS, Baker C, Chaput G, Finelli A, Kupets R, Look Hong NJ, Gagliardi AR. Preferred labels and language to improve communication about lesions at low risk of progressing to cancer: Qualitative interviews with patients and physicians. BMJ Open 2025;15:e087484. ALSO, see one-page infographic summary of review and interviews.
3. Lyons MS, Chaput G, Finelli A, Kupets R, Look Hong NJ, Wright FC, Gagliardi AR. Labels, language and other strategies to improve communication about ductal carcinoma in situ of the breast: a national Delphi survey. International Journal of Breast Cancer 2025 (under review). ALSO, see one-page infographic summary.

IMPLICATIONS

- Prior research endorsed changing the DCIS label, but had not fully explored label preferences, or identified other ways to improve communication about DCIS
- Clearly, changing the DCIS label alone is insufficient, and explaining DCIS using the language and other strategies identified by this research may improve communication about DCIS
- Some limitations must be considered. The number of panelists, although typical of consensus surveys, was small, and as volunteers, their views may have been biased. The findings may not be relevant to women or professionals from outside of Canada with differing healthcare systems
- Still, these results could be promoted to physicians so that they employ language and other strategies that may reduce confusion and anxiety among women with DCIS
- Cancer nomenclature agencies may wish to reflect on these results when considering changes in the naming of low-risk forms of DCIS given precedence for low-risk lesions of the bladder, cervix and prostate

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