

# Improving Communication About Low-Risk DCIS

***Just the word 'cancer' frightens most people because of what they have heard or read about it.***

– healthtalk.org

An Australian study<sup>1</sup> found that terminology used to describe DCIS impacts the fear levels and treatment preferences for women.

This information is based on current research, and will be updated regularly. The following charts were created by the COMET Study<sup>2</sup> Patient Leadership Team (PLT), with feedback from others, to help healthcare providers (HCPs):

- Distinguish “low-risk” from high-risk DCIS
- Reduce patient and public fear and confusion
- Educate and empower patients with more accurate language and information to foster informed decision-making

CURRENT CONCEPT/LANGUAGE	SUGGESTED CONCEPT/LANGUAGE
DCIS is a single condition.	Different kinds of DCIS have different levels of risk.
DCIS is not well understood or studied.	Research is underway to learn how to better differentiate low-risk from higher risk DCIS.
DCIS treatment is one size fits all.	DCIS treatment is not one size fits all. Low-risk DCIS may require less aggressive treatment without compromising effective outcomes. The COMET study is trying to determine this.
Current treatment goal is to reduce “risk” of a future DCIS and/or invasive breast cancer.	Treatment goals should always include quality of life, patient preferences and survival.
Survival benefit is often not discussed.	For low-risk DCIS, some new studies indicate 10-year survival may be the same after initial surgery even without radiation therapy. <sup>3</sup>
Relative risk reduction is often mentioned in studies and media. <sup>4</sup>	Absolute risk reduction should always be included <sup>5</sup> to avoid exaggerated perceptions of treatment benefits or harms. Absolute Risk = actual risk for any member of a studied group.
Side effects or harms of treatments may not be fully discussed.	All treatments have potential side effects. It is important to understand both short-term and long-term effects of each treatment to decide if the benefits outweigh harms for each person.
DCIS “progresses” to invasive breast cancer <b>or</b> DCIS is a non-obligate precursor to invasive breast cancer.	The natural history of DCIS is unknown. Researchers are trying to learn if a future breast cancer or DCIS is related to the original DCIS, or not.

Please consider using the suggested terms and concepts to help set the correct expectations for those who are diagnosed with DCIS.

***Thank you for helping to improve communication about DCIS!***

# Improving Communication About Low-Risk DCIS

CURRENT TERM	SUGGESTED TERM
Comorbidity	Presence of other chronic diseases or health condition
DCIS (too general)	'Low-risk' DCIS (low or intermediate grade DCIS) and 'higher grade' DCIS
Cancer/Pre-invasive/ non-invasive	Abnormal cells, Breast condition
Disease	Condition
Endocrine therapy	Endocrine (Hormone-blocking) therapy
Mortality/death	Survival (most survive)
Morbidity	Side effects
Radiotherapy	Radiation treatment
Recurrence	Future DCIS or invasive breast cancer
Risk	Chance
Stage 0 breast cancer	Condition/low-risk DCIS/higher-risk DCIS
Survivor	Person diagnosed with low-risk/higher risk DCIS
Tumor	Growth/lump/lesion/mass you can feel (palpable)
Watchful waiting	Active surveillance/careful observation/monitoring

<sup>1</sup> McCaffery K et al. <http://bmjopen.bmj.com/content/5/11/e008094.short>

<sup>2</sup> The Comparison of Operative to Monitoring and Endocrine Therapy (COMET) study compares treatment choices for people with low-risk DCIS. [www.dcisoptions.org](http://www.dcisoptions.org)

<sup>3</sup> Narod SA et al. <https://www.ncbi.nlm.nih.gov/pubmed/26291673>

<sup>4</sup> <https://www.healthnewsreview.org/toolkit/tips-for-understanding-studies/absolute-vs-relative-risk/>

<sup>5</sup> <http://scienceblog.cancerresearchuk.org/2013/03/15/absolute-versus-relative-risk-making-sense-of-media-stories/>

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