



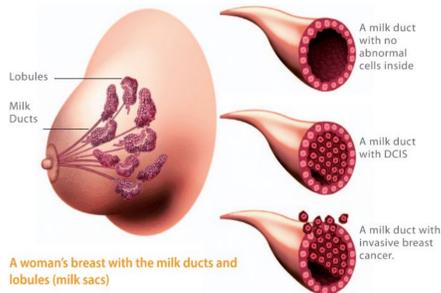
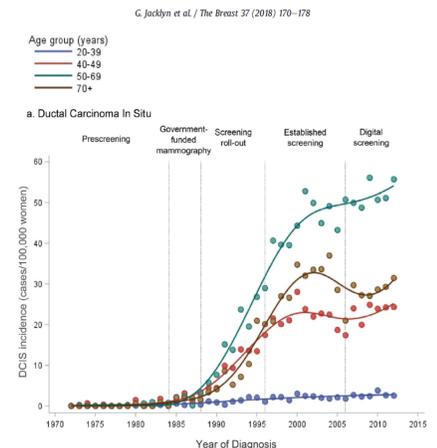
Treating (or Monitoring?) Low-risk Ductal Carcinoma in Situ: Focus Groups About Women's Views

Jolyn Hersch, B Nickel, A Dixon, J Jansen, C Saunders, N Houssami, A Barratt, A Spillane, K Stuart, C Rutherford, G Robertson, E Wylie, K McCaffery. University of Sydney, University of Western Australia, BCNA

@jolynehersch

Background

- Organised breast screening has greatly **increased ductal carcinoma in situ (DCIS) incidence globally**... e.g. see NSW data →
- Internationally, DCIS accounts for **~20% of all screen-detected breast cancers**.
- Recognition that some DCIS lesions might **remain indolent** for many years has led to **concern about overtreatment**.
- Overseas clinical trials currently assessing **safety of active monitoring** for low-risk DCIS will generate much-needed high-quality evidence re new approaches.
- Women may not be aware** of DCIS and the dilemmas around management.

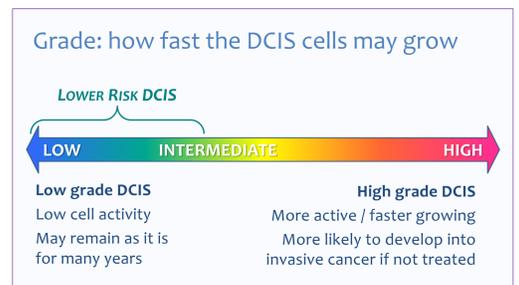


Aim

- We aimed to **explore women's understanding and views about DCIS** and current and potential future **management options**.

Methods

- Community-based sample, recruited by telephone, of **56 women aged 50-74** with **no personal history** of breast cancer/DCIS.
- 6 age-stratified **focus groups** around Sydney.
- Sessions incorporated a **purpose-designed presentation** explaining: the nature of DCIS, current standard management, uncertainty re progression, ongoing clinical trials of monitoring for low-risk DCIS.
- Participants shared thoughts, feelings, questions** in response to info.
- Discussions were audio-recorded, transcribed and analysed thematically.



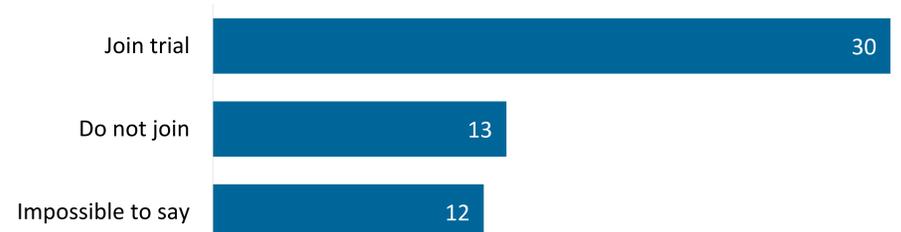
A slide from the focus group presentation

Results

- Very **few participants had heard of DCIS**.
- Many women **interested in being monitored** if diagnosed with low-risk DCIS, to **avoid unnecessary treatment** – *“You always have that backup under the active monitoring. If something does go astray you’ve still got treatment as an option... I don’t know that anyone really wants to...put their body through all that trauma if they don’t have to.”*
- Others expressed a stronger **preference for immediate treatment**, showing concern about **psychological implications of not treating** – *“But you’ve got the psychological worry the whole time... at the back of your mind there’s this little person on your shoulder going, ‘You’ve got cancer cells in there! Your days are numbered!’”*
- Although women mostly **supported clinical trials** of monitoring (and just over half would join if invited*), they also had important concerns/ misconceptions about such trials.
- Some participants **struggled to understand the need for randomisation** – *“So how’s that any different from just having a group of women that nominate not to have treatment and monitoring them? ... How’s that different...through a clinical trial..?”*
- Many would be **reluctant to leave their management to chance** – *“So from a selfish point of view I’d want to make my own choices.”* – including some who **felt strongly against surgery** if monitoring were considered viable – *“I wouldn’t go into the trial because they might put me in the surgery group and I wouldn’t want the surgery group.”*

*Written questionnaire at end of focus group

Imagine you’ve been diagnosed with low-risk DCIS and invited to join a clinical trial in which you’d be randomly allocated to either receive standard treatment (including surgery) or have active monitoring instead. **If you really had to pick an answer right now, which option are you leaning towards?**



Conclusions

- Public awareness of DCIS remains very limited** (despite breast cancer screening being established for 30 years now).
- Most focus group **participants gained a reasonable understanding** of the issues during the session, and we found **substantial interest in monitoring for low-risk DCIS**.
- Effective communication is essential to facilitate **informed decisions** about screening, treatment and trial participation, and to implement future changes in practice.

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