Early diagnosis and optimising treatment: How consumers can join forces and accelerate progress

The Australian Experience

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JOINING FORCES – ACCELERATING PROGRESS
UICC global cancer control WORLD CANCER CONGRESS
Hosted by Cancer Council Australia
www.worldcancercongress.org

Who is Breast Cancer Network Australia?

Breast Cancer Network Australia

Vision Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.

Mission

- support
- inform
- represent
- connect

BCNA's Consumer Engagement

Breast Cancer Network Australia

- National membership of 99,000
- Online network membership of 13,000
- Review & Survey Group of 2,500
- *The Beacon*
- Seat at the Table − 81 Consumer Representatives
- Social media − 37,000 Facebook followers

Information

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- Information empowers consumers
  - engages them in treatment decisions
- BCNA's *My Journey Kit* reaches 82% newly diagnosed
  - 87% within one month of diagnosis
  - 61% said it helped them make treatment decisions
- Website

"I was so glad to be informed and encouraged to ask questions, and helped through the material about what questions to ask. I found that knowledge empowered me greatly."

Consumer-led research

Review & Survey Group

- 2,500 participants
- 28 invites to participate in research in 2014
- reviewing patient materials
- studies and trials
- eg Cancer Australia survey radiation

"We have been recruiting women through our clinic for 16 weeks. Within the first 24 hours of the email to Review & Survey Group members, the number of study participants has increased by 50 per cent!" – Researcher

"My experiences benefit others, and are therefore not lost. Some of the studies also reaffirm just how well I've handled the whole experience.
I really am doing ok, and sometimes it's good to stop and realise that."- Karen

Review and Survey Group

Benefits

- Online
- Cost effective
- Timely
- Women keen to participate
- Questions women want to know
- Timely sharing of results with women
- Credible
- Underpins advocacy

Breast Cancer Network Australia

Recent examples

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Women's experience of diagnosis through screening mammogram

- Surveyed women using Review & Survey Group
- 236 women participated (survey open for one week)
- Provided understanding about the experience of diagnosis

Financial impact of secondary breast cancer (SBC)

- Aim was to understand experience of SBC
- Found that 60% of women experienced financial difficulties
- Have been able to present the findings at this meeting

Seat at the Table

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Processes

- Training
- Currently 81 women trained
- Matching women to opportunities
- National health system advisory committees
- Research groups
- State and local projects
- Ongoing support
- Feedback
- Promotion

Outcomes

- Cancer Australia's clinical guideline update
  - Management of CNS metastasis
  - 2 Consumer Reps
  - Provided insight on the lived experience of women with SBC

"My interaction with the BCNA consumer representative was very valuable and gave me a lot of insight into the consumer perspective, especially the impact of current 'successful' treatments on quality of life."

Consumer driven advocacy

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- Planned and reactive
- Undertake research to inform and validate campaign
- Power of the membership
- Voice of the women
- Systemic level
- Strategic
- Collaborative
- Role of online and social media

SBC Awareness Day

- Messages shared through social media
- 175,000 people saw it

Online Network

- Breast reconstruction group – 600
- Sharing stories, posting photos

Information Forums

- Expert presenters
- 200+ women
- Reconstruction concerns

Access to high cost treatments

Kadcyla for HER2+ women

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- Submissions to PBAC –
- Feedback from women about the benefits
- Evidence based – work with MOGA
- Roundtable meeting – Govt (PBAC), Pharma, clinicians, BCNA
- Liaise with pharmaceutical industry
    - advocate for patient access programs
- Media to highlight financial impact on women

Thank you

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