



# Valuing empowered consumers

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Breast Cancer Aotearoa Coalition



# My leadership journey

- Read a poster “*Annual mammograms from 40–50 yrs*”
  - Clear at 40, aggressive breast cancer by 41
- Motivated to help others
  - Joined a peer support group
- Soon discovered health system gaps
  - Obstacles to timely, effective detection, treatment and care
  - Growing awareness among clinicians, patients and survivors

# My leadership journey

- 2004 Forum
  - NZ & Australian breast cancer doctors & BC groups
    - Raise awareness, identify issues, develop strategies
  - Care being transformed in USA and Australia through clinician – advocate collaboration
  - NZ needed many reforms to improve patient care & outcomes
  - Key: evidence-based advocacy

# Breast Cancer Aotearoa Coalition

- 12 breast cancer groups at 2004 Forum → BCAC
- 2006 – charitable incorporated society
- 2016 – >30 BC groups around NZ
- Run by volunteers who have experienced BC
- Employ admin & comms staff
- Funding – donations, trust grants, MoH grants

# BCAC formation, 2004

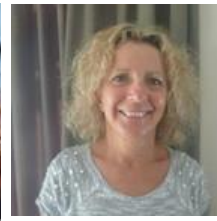




# BCAC Committee & staff, 2016



*Together we're stronger*  
Tangata tū pakari tonu



# BCAC's key objectives

- *Make world-class detection, treatment & care accessible to all with BC in NZ*
- *Offer info & support to empower BC pts to make informed decisions about treatment & care*
- *Provide evidence-based voice for those with BC in NZ*

# What has BCAC influenced?

- *Standards of Care for BC Patients in NZ*
- Availability of breast screening & age band
- Faster Cancer Treatment
- Cancer Nurse Co-ordinators
- Psychosocial support



# What has BCAC influenced?

- Access to medicines
  - Herceptin, taxanes, Als etc.
  - Ongoing issue for cancer
    - Many effective meds not funded
    - Game-changers are high-cost
    - PHARMAC funding increases needed
    - Separate cancer meds fund needed



# What has BCAC influenced?

- Breast reconstruction surgery
- Fertility treatment
- Lymphoedema treatment
- Provision of good patient info



# What has BCAC influenced?

- Provision of good patient info
  - *Step by Step* patient support packs
    - Developed collaboratively with expert clinicians
    - Treatment diary, info book, journal
    - Over 10,000 provided free to newly diagnosed pts
  - *Kiwi Stories of Breast Cancer*, 14 videos
    - Patients, doctors, nurses discuss many aspects of BC
    - Over 12,000 views



# What has BCAC influenced?

- Provision of good patient info
  - Website [www.breastcancer.org.nz](http://www.breastcancer.org.nz)
    - Comprehensive info
  - Facebook page & group
    - Forum for discussion
  - Metavivors group for advanced BC
    - Facebook page – support and info
    - Now producing 11 videos on advanced BC

# How can clinical leaders support consumers?

- **Train us**
  - Teach us about the system, stakeholders, decision-makers, opportunities
  - Educate us - conferences with good advocate programmes, e.g. ANZBCTG, SABCS
- **Inform us**
  - Keep us in the know – we can raise issues you can't
- **Trust us**
  - Our experiences, knowledge & voices can catalyse reform

# How can clinical leaders support consumers?

- **Include us**
  - Professional meetings, clinical leadership committees (a seat at the table)
- **Listen to us**
  - Seek our input, empower our voices. Good ideas from experience
- **Stand with us**
  - Dare to speak out. Combined expert/consumer voice is powerful!  
Credibility & real world impact



# My goals as a consumer leader

- Ensure our health system does its best to provide world-class treatment & care
- Empower patients – improve their cancer journey and outcomes
- Represent patients with an evidence-based voice
- Work collaboratively with clinicians & officials to achieve positive reforms

# Why grow consumer leaders?

- Trained, well-informed, motivated reps can catalyse system reforms
- Highlight issues to decision-makers, public, politicians
- Explain impact on people's lives
- Provide honest feedback on care provided
- Essential in achieving patient-centred care

# What are we seeking with providers?

- Collaboration, trust, synergy
  - Working together empowers us to achieve more
- BCAC motto:

*Tangata tū pakari tonu*

**Together we're stronger**

# Breast Cancer Standards Working Group



# Survival as a consumer leader?

- Satisfaction in seeing positive change
  - Issues we have raised eventually get action
- Seeing patients empowered
- Working with the awesome women of BCAC
- Collaborating with great clinicians
  - Prepared to stand up for their patients

# Changes in last 10 years

- Greater trust of consumers in *some* clinical leaders
  - “Good guys” get involved, reach out, listen
  - “Old school” reluctant to collaborate, “*this doctor knows best*” attitude
- Still low consumer involvement at governance level



# Biggest stumbling block

- Fear of consumers
  - That we'll do something random or embarrassing
  - That we'll compromise credibility
  - That we'll speak the awful truth
    - Ministers hate bad news
- Contrasts with US & Australia
  - Consumers are valued

# Challenges ahead

- Establishing consumer positions across health system
  - Thinking shift from providers, policy & decision-makers
- Supporting consumers
  - Training, mentoring & succession planning
  - Build a robust population of representatives

# What have we learned?

*Never doubt that a small group of thoughtful,  
committed citizens can change the world;  
indeed, it's the only thing that ever has*

Margaret Mead