How can we fast track recruitment for research projects?

- Sometimes takes years to find the right people for a research project
- Traditional methods of researchers in waiting rooms with clipboards
- Time consuming, laborious & costly
Register4 - overview

• An online register where you can sign up to participate in breast cancer research

• An initiative of the National Breast Cancer Foundation

• Brings people together with breast cancer researchers for the joint purpose of finding answers sooner

• More research = more answers to breast cancer
What is involved for members?

Voluntary online registration

Welcome notification

Invitation to complete health and lifestyle questionnaire

Email and web-based communication about approved research

Expression of interest online

Consented details forwarded to investigator

Commences the formal study recruitment process

Findings communicated back to participants and the community
What is involved for researchers?

Voluntary online registration

Application for access to members

Access Committee

Approval of project

Communication to members

Receive approved members’ contact details

Further screening and project implementation

Commitment to respond to each responding member
Confidentiality

• All member’s details used for the sole purpose of contacting them to be part of breast cancer research
• Adhere to State and Federal privacy laws
• Data security audit
• Register4 will not be used as a fundraising vehicle
Impact

• Over 30 000 members in 2 years
• Members from 18 to 100 years, male, female and transgender, representing all Australian States & Territories
• Have recruited for 8 studies in 2012, some within 24 hours
• Some projects are already recruiting for projects beyond breast cancer eg: ovarian cancer, bowel cancer
Projects

- Projects vary depending on the research. For example: sexuality; risk factors; diet; physical activity; mammographic density.
- Projects may want survivors, control groups, carers, family history etc.
- It could be completing a questionnaire or something more involved such as a blood sample.
- Always a member’s choice.
Empowering members

Thanks for such a great service connecting survivors of this disease to the latest research opportunities. Makes me feel more empowered against such a big challenge!

(Community member, Oct 2012)

We were delighted to use Register4 to fast track recruitment for our project. It would have taken us about a year to find the people Register4 found in a day.

(Professor Sharon Kilbreath, Sept 2012)
Community engagement

- Prelaunch workshops
- Focus groups
- Women’s Advisory Network
- Community Reference Group
- National launch and events to maximum media exposure
Communication partners
Register4 officially launched today in Martin Place and we’ve already had over 4,000 registrations! Massive thanks to everyone who turned up today, especially Gail Kelly and her team from Westpac. Now we need your help. Spread the word and help us hit 1,000,000!

Vanessa Austin: That is excellent to get that many registrations. I registered today and I’m being interviewed by my local newspaper on Wednesday regarding genetic testing and I am going to include Register4 in my story as well as NBCF and Pink Hope. Register4 is great news for us all. Well done!! 💕

Mary Bolwell: Have registered with this, think it’s really a good cause.

Paula Walsh: Amazing - I will be encouraging others to join in!

Yvonne Cheong: I’m happy to be apart of this research I hope we find a cure.

Jayne Anthony: being a survivor of 12yrs. I want to help others I’m registered.
Engaging researchers

- National workshops pre launch
- Involvement in committees
- E-newsletters
- Word of mouth
- Conferences
Challenges

• Robust IT platform
• Committee engagement - time consuming but essential
• Relevant & timely member communication
• Self selection to participate
• Meeting member expectations for project involvement
• Online application only
• Sustainable business model
Lessons learned

• Choose the right IT platform
• Have the right expertise to deliver
• Listen to stakeholders – ongoing market research
• Clear communication goals and call to action
• Reinforce NBCF branding
• Learn from others eg: AOW
Enduring resource with future adaptations

- Partnerships between women and researchers
- Positive impacts on research
- People able to take an active part in research
- Potential to also answer questions about:
  - other women’s health issues & diseases