Harnessing the community to accelerate cancer research outcomes

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Abstract code: 313

Disclosure of Interest: None Declared
The issue:

How to fast track recruitment for cancer 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:

An overview

• An Australian online register where you can sign up to participate in cancer research
• Based on highly successful, US-based Army of Women
• Brings people together with cancer researchers for the joint purpose of finding answers sooner
• Less time on recruitment = more time for research
How does it work?
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
How does it work?

For researchers

1. Voluntary online registration
2. Application for access to members
3. Access committee
4. Approval of project
5. Communication to members
6. Received approved members’ contact details
7. Further screening and project implementation
8. Commitment to respond to each responding member

Alison J. Butt, National Breast Cancer Foundation

Melbourne, Thursday 4th December, 2014
The impact:

- Launched in 2010 for breast cancer research; opened up to all cancers on World Cancer Day, 2014
- Over 45,000 members
- Members from 18 to 100 years, representing all Australian States & Territories
- Membership is predominantly women
- Have recruited for 30 studies in total, some within 24 hours
- Projects across many different cancers, e.g. ovarian, bowel, breast
- It could be completing a questionnaire or something more involved such as a blood sample

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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.
(Researcher member, Sept 2012)
Community engagement
Enduring resource:

- New approach to cancer research
- Potential to extend to other diseases outside of cancer
- Development of the Health & Lifestyle Questionnaire
- Linkage to medicare, PBS
More information:

www.register4.org.au