

# Register4 – an online community to fast track breast cancer research

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[register4.org.au](http://register4.org.au)

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# What is Register4?

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- An online register where you can sign up to participate in breast cancer research
- An initiative of the National Breast Cancer Foundation launched in October 2010
- Brings people together with breast cancer researchers to fast-track research
- More research = more answers to breast cancer

Register4 - helping to find more answers to breast cancer



Join us today!



Register4 brings together researchers & willing participants who share one common goal - advancing breast cancer research

*I'm an individual*

Register4 is Australia's first online community for breast cancer research volunteers. By joining us you could help researchers spend less time and money finding volunteers, and more time finding a cure.

Find out more! +

*I'm a researcher*

Register4 recruits volunteers around Australia, with and without breast cancer, for breast cancer research projects. To apply for access to Register4, you must first become a researcher member.

Find out more! +

The Register4 community

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members and counting ...



# How do researchers typically recruit?

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- With large inputs of time and money
- With variable success
- Hanging out in waiting rooms with clipboards



# How Does Register4 Enable Recruitment?

- It is an online register
- It takes <5 minutes to sign up
- Data is secure and confidential
- Members can access a variety of research projects and opt into any of interest
- Based on a US model, the Army of Women



# What is involved for members?

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# What is involved for researchers?



# Current Membership Profile

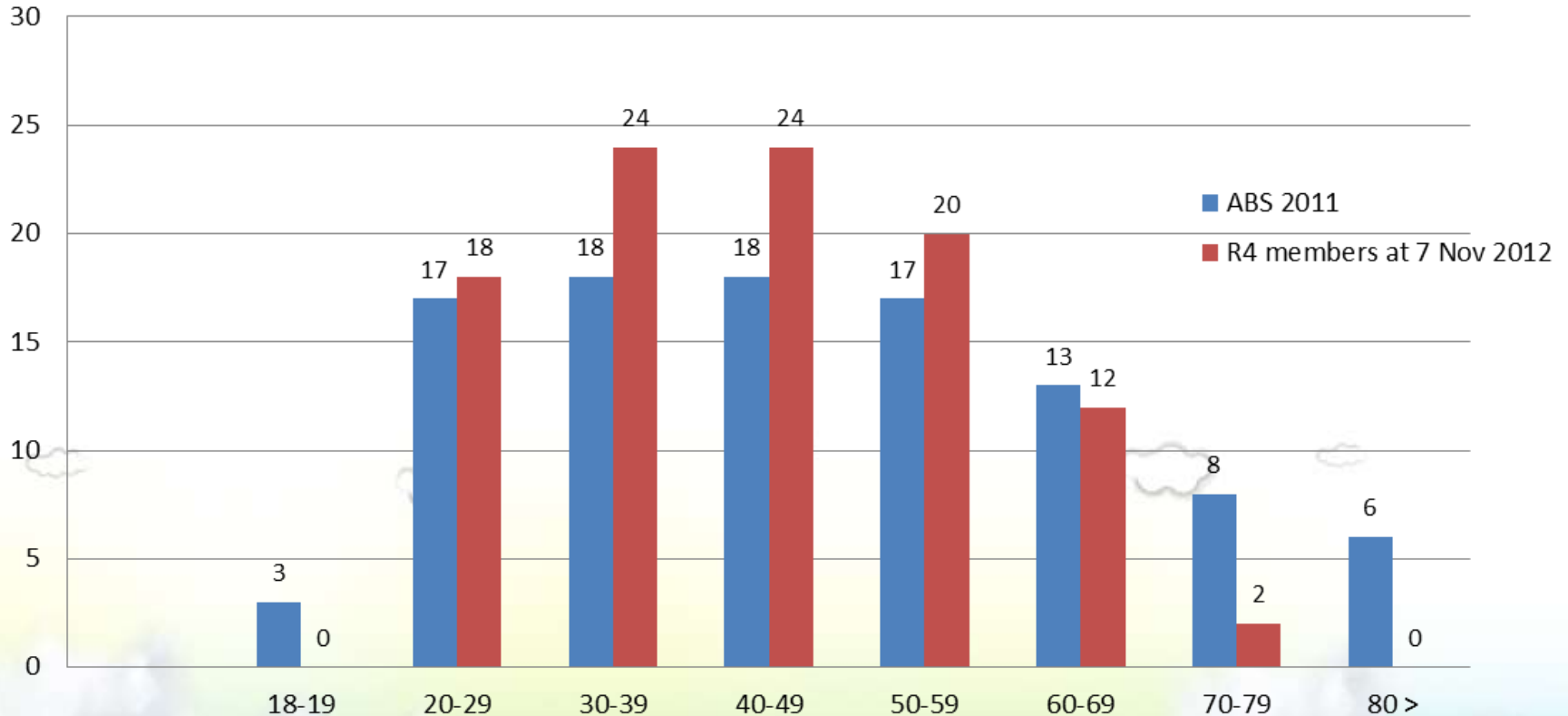
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- At 7 May 2013, there are 30,803 members.
- 98% are female.
- Average age 44 years.
- 200 new members joining a month.
- 25% have actively engaged in research to date.



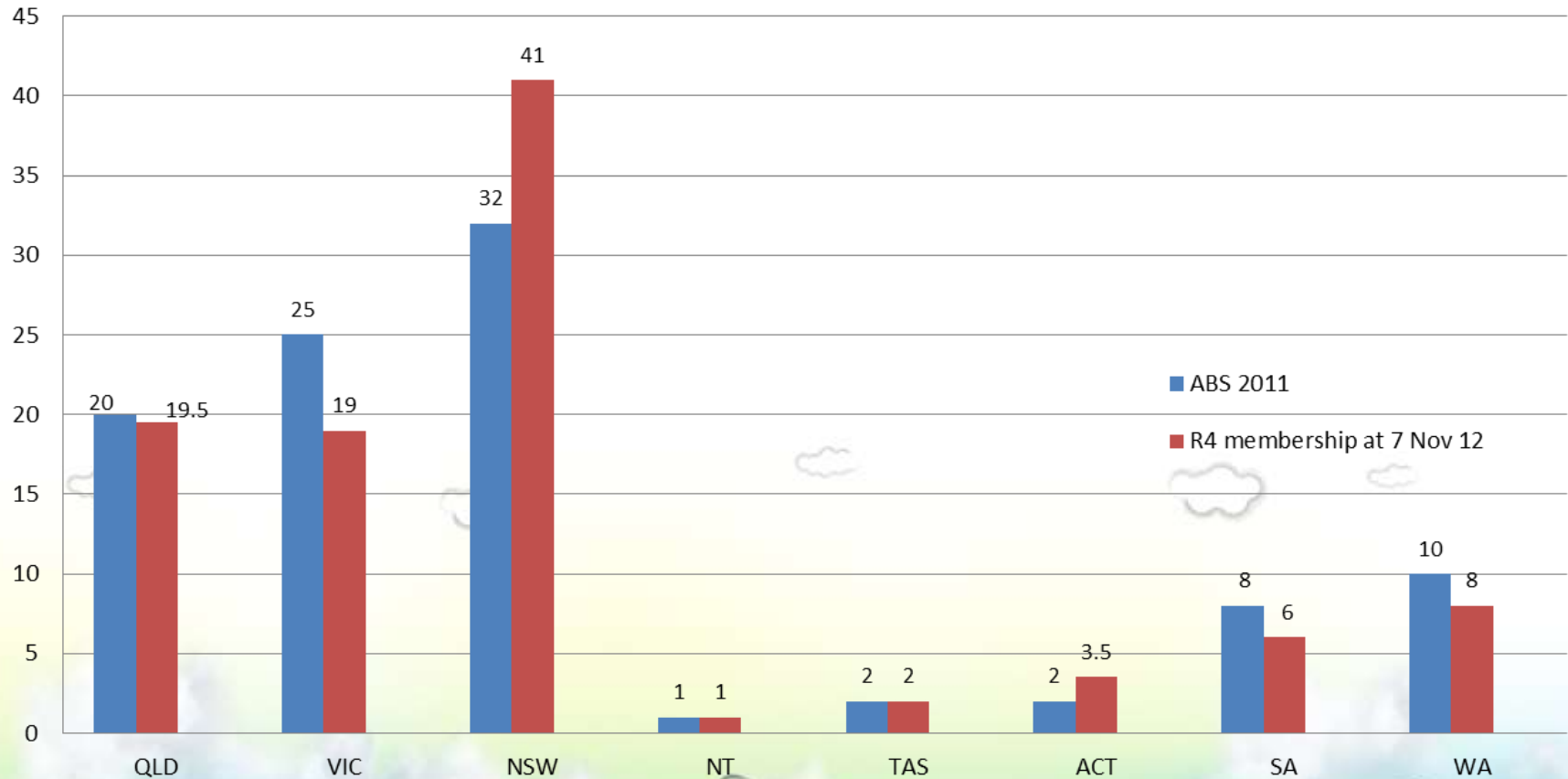
# Current Membership Profile

Member Age ranges compared to ABS 2011 female age range



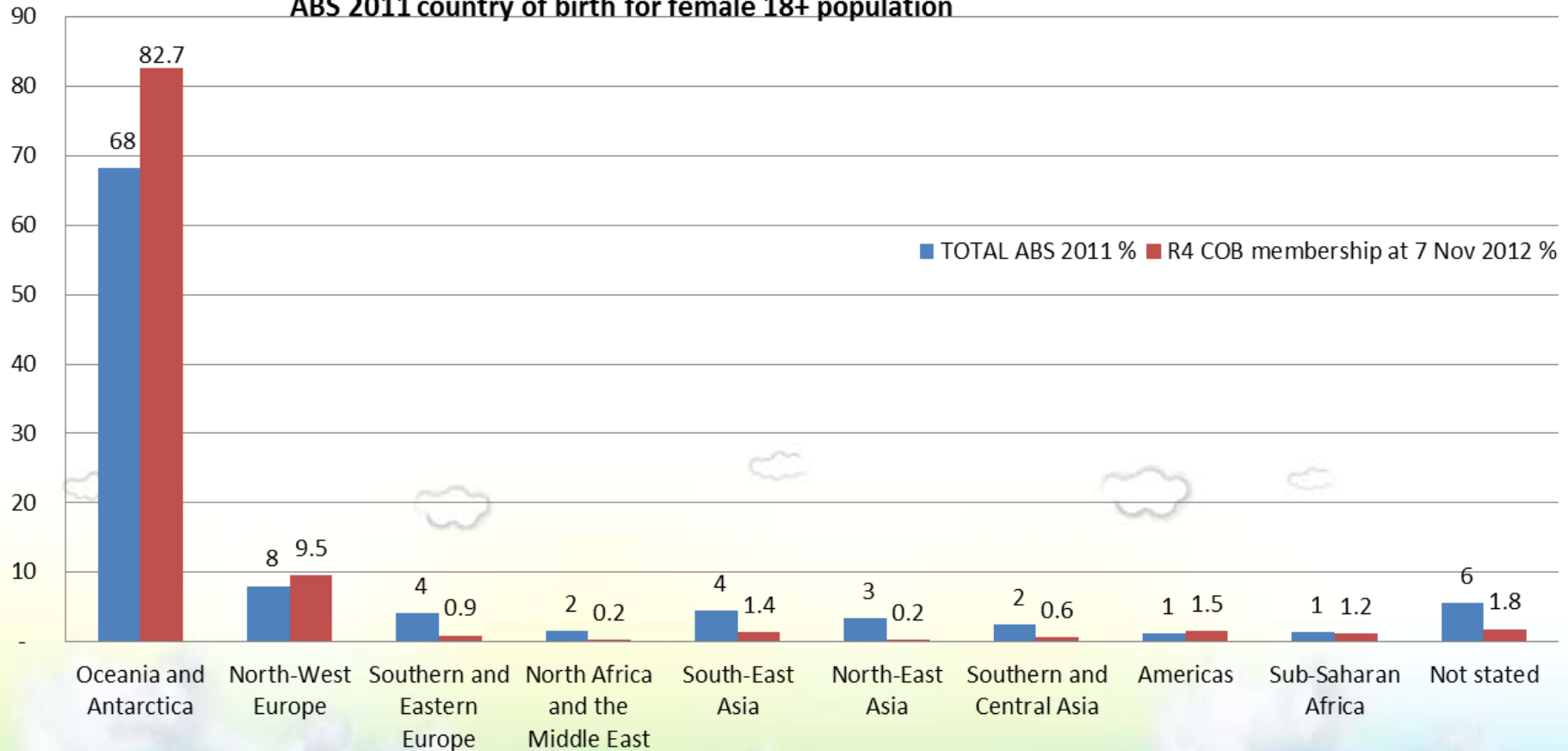
# Current Membership Profile

Comparison of ABS 2011 female State/Territory population to Register4 membership State/Territory population at 7 Nov 2012



# Current Membership Profile

Comparison of country of birth at 7 Nov 2012 as a % with  
 ABS 2011 country of birth for female 18+ population



# Health & Lifestyle Survey

- Online survey open to all members
- Completed by over 7,500 members (~25%)
- Survey content includes:
  - Socio-demographics, height, weight
  - Smoking, alcohol, exercise, psychological distress
  - Reproductive/contraception history
  - Health conditions/medications recently used
- Survey data available to researcher members

# Health & Lifestyle Survey

## Demographics

- 99% female
- 47% university degree or higher
- 81% born in Australia
- 5% speak language other than English at home
- 38% annual household income \$100,000 or more
- 73% have private health insurance
- 66% have had a child

## Risk factors

- 5% current smokers, 33% ex-smokers

# Health & Lifestyle Survey

Doctor ever told have any of the following:

- 21% breast cancer
- 25% depression
- 17% anxiety
- 20% asthma
- 17% high blood pressure
- 17% high cholesterol
- 11% thyroid problems
- 1% heart disease

# Research Projects

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- Projects mostly breast cancer focused and vary depending on the research (e.g. 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 providing a blood sample
- Always a member's choice

# Examples of Results Achieved

Project	Selection Criteria	Impact
Physical well being for women with metastatic breast cancer	Women with metastatic breast cancer & control group (Sydney)	Recruited control group in a day – normally taken researcher a year
Australian Breast Cancer Family Study	Women with strong family history (national)	A few weeks to get 600 women – normally taken 2 years
Cancer & Sexuality	Cancer patients and their partners (national)	Almost 400 people in a month – normally taken 2 years
Investigating patient preferences	Breast cancer survivors (national)	450 in 3 days, would have taken about 3 months
Treatment of post cancer fatigue	Breast cancer survivors (Brisbane)	Partially recruited but challenges with specific location and selection criteria



# Community engagement

- Prelaunch workshops
- Focus groups
- Women's Advisory Network
- Community Reference Group
- National launch and events to maximum media exposure
- Social media (Facebook, twitter)



# Researcher Engagement

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



**REGISTER4 CAN FAST TRACK YOUR RESEARCH  
BY FINDING THE PEOPLE YOU NEED.**

AN INITIATIVE OF THE NATIONAL BREAST CANCER FOUNDATION  
VISIT [REGISTER4.ORG.AU](http://REGISTER4.ORG.AU) TO JOIN AS A RESEARCHER MEMBER.



Register4 is an online community of people who are willing to participate in research

[register4.org.au](http://register4.org.au)

# Empowering members

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*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)*

# Impact

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- Over 30,000 members in 2.5 years
- Members from 18 to 100 years, male, female and transgender, representing all Australian States & Territories
- Have recruited for 12 studies, some within 24 hours
- Some projects are already recruiting for projects beyond breast cancer eg: ovarian cancer, bowel cancer

# Learnings & Challenges

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- Sustainable funding model
- Robust IT platform
- Equity of access – online only
- Representativeness
- Ongoing member engagement
- Embedding in research system
- Moving beyond breast cancer

# Communication partners



[www.register4.org.au](http://www.register4.org.au)