Register4 –
an online community to fast track research

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REGISTER4 – INTRODUCTION

Register4 is Australia’s first online community where anyone aged 18 years and over, with or without breast cancer, can participate in breast cancer research. Launched in October 2010, it is an initiative of the National Breast Cancer Foundation, which brings people together with breast cancer researchers for the joint purpose of finding answers sooner.

Register4 is an example of technological innovation that has been welcomed by a community of nearly 30,000 members who now have an opportunity to take an active role in breast cancer research. Almost a quarter have participated in the Baseline Health & Lifestyle Questionnaire which aims to explore the relationship between breast cancer and potential links between factors such as lifestyle and genetics. Further, an example of proof of concept was successful recruitment for a project, ‘Physical well being for women with metastatic breast cancer’ in just 24 hours. Meeting the expectations of members and researchers is critical to its success, therefore engagement and feedback with these groups will play an important role.

While most current projects on Register4 are related to breast cancer, it is envisaged that over the longer term, Register4 will also support research into other diseases. www.register4.org.au

REGISTER4

Register4 is Australia’s first online community where anyone aged 18 years and over, with or without breast cancer, can sign up to participate in breast cancer research. Launched in October 2010, it is an initiative of the National Breast Cancer Foundation, which brings people together with breast cancer researchers, for the joint purpose of finding answers sooner. Our vision is that Register4 will be an enduring resource and become Australia’s foundation stone in the global data bank for breast cancer research. It also has the potential to answer questions about other diseases. www.register4.org.au

The objective of Register4 is to provide a unique national research resource that will contribute to saving lives by accelerating our understanding towards the prevention and cure of breast cancer. Register4 aims to:

- increase opportunities for people to participate in approved research;
- assist researchers to contact people who may be willing to consider taking part in approved projects;
- help increase recruitment to existing projects; and
- provide lifestyle and family health history information about people for approved research.

COLLABORATION

Register4 is about partnerships between people and researchers, working together to make research happen faster. In the US, a similar initiative was launched in 2008, www.armyofwomen.org. Their experience has indicated that many of their projects are recruiting women within 24 hours and have been greeted with enthusiasm from researchers. They have recruited for over 60 projects to date covering a broad range of research areas including, translational, clinical, epidemiology, public health, molecular biology, genetics, psychology, mental health, detection and diagnosis, sexuality, quality of life and prevention.

REGISTER4 AT WORK

Researchers submit projects for consideration via the Register4 website. All projects are assessed by the Register4 Access Committee to determine their relevance to breast cancer and to ensure that they meet the highest standard of research quality and integrity. Prior to being offered to Register4 members, projects must be peer reviewed, ethics approved and have funding. Approved projects are emailed to Register4 members and they express interest online in finding out more about a project. At this stage they consent for their contact details to be released to the researcher. If a member meets the project criteria and chooses to participate, they provide their formal consent to the researcher. After the project is implemented, a summary of the results are published on the Register4 website for the benefit of all.

Participation is voluntary and it is always a member’s choice to participate in a project. Projects will vary. It may be completing a questionnaire to something more involved like providing a sample of DNA such as a strand of hair. Register4 adheres to all State and Federal privacy guidelines.
GETTING RESULTS
Since the launch in October 2010, there are nearly 30,000 Register4 members and almost 7,000 have completed the Baseline Health & Lifestyle Questionnaire which was offered to members in October 2011. The questionnaire is a type of epidemiological research which was developed by some of Australia’s leading cancer researchers. Through this questionnaire, the research will be looking at how health and lifestyle factors as well as genetics may influence breast cancer risk, by following up Register4 members over time. This is very important because we know that breast cancers are diseases of the genes, but each breast cancer sub-type is different and a complex interaction between genes and the environment. Results from the Questionnaire will also provide important guidance for the design of future studies, and will facilitate researcher’s responsiveness to new breast cancer issues as they arise. The Questionnaire asks about medical and reproductive history, breast cancer and screening, the pill and HRT, exercise and general health and lifestyle. It takes about 20-30 minutes to complete.

Another project from University of Sydney researchers, ‘Physical well being for women with metastatic breast cancer’ recruited participants via Register4 in less than a day. Professor Sharon Kilbreath required between 20-120 women from the Sydney area, half without breast cancer and half with metastatic breast cancer. 80 women without breast cancer and 16 women with metastatic breast cancer expressed interest within twenty four hours. Professor Kilbreath advised, “Without Register4, it would have taken us about one year to recruit the number of healthy women for our project. Register4 was able to find a broad group of women in less than a day. It was an efficient process and really fast tracked our recruitment.”

COMMUNITY ACCEPTANCE
Register4 is an example of using innovative technology to bring people together with researchers to help fast track research. It gives people an opportunity to take an active role in research. Register4 also uses social media to engage members. There are nearly 15 000 followers on facebook which also provides members a forum to share their personal story and encourage others to join. Members come from across Australia and from all over the world. 98% are female.

While there is now a solid base of community support for Register4, engagement with the Research community is increasing. Researchers have welcomed the initiative that is assisting them to find people with unique characteristics in a shortened timeframe. While some projects are seeking participants to complete a questionnaire, others are requesting members to provide a blood sample and/or more invasive techniques. Initial research with the Register4 community indicates they are keen to use Register4 to assist them in recruitment for their projects.

![% Comparison of Register4 members at 1 March 2012 by age with ABS 2010 female population 18+ years](image)

The above table indicates the age range of Register4 members compared to Australia Bureau Statistic data 2010.

THE FUTURE
Ensuring Register4 meets the expectations of members and researchers at the outset, and over the longer term, is critical to its success. Ongoing evaluation of member and researcher experience will assist to adapt Register4 to ensure its relevance.

While current projects are being sort from breast cancer researchers, it is envisaged that over the long term Register4 will also support research in other diseases; in women’s health, multiple sclerosis, depression and prostate cancer for example.
ABOUT THE AUTHOR(S)

Dr Alison Butt, BSc (Hons) PhD
Director, Research Investment, National Breast Cancer Foundation

In September 2011, Dr Alison Butt joined the National Breast Cancer Foundation as Director, Research Investment after nearly 20 years experience as a cancer researcher, including most recently as a Group Leader in the Cancer Research Program at the Garvan Institute of Medical Research in Sydney. She has also held a conjoint appointment in the Faculty of Medicine at the University of New South Wales since 2004.

Having gained a BSc (Hons) and PhD in the UK, Alison came to Australia in 1996 to pursue postdoctoral studies at the Hanson Centre for Cancer Research in Adelaide. She moved to the University of Sydney in 1998, and then the Garvan Institute in 2004. Alison’s research interests have been in the molecular regulation of cell death and its role in drug resistance in breast cancer, and she has published over 40 research articles in this area.

In 2005, Alison was elected to the Board of Directors of the Australian Society for Medical Research (ASMR) and served as the ASMR President in 2010. The ASMR is the peak professional body representing the health and medical research sector in Australia, driving scientific, political and public advocacy, as well as professional development programs on behalf of the sector. She currently serves on the Board of Research Australia.
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