



2016 ANNUAL REPORT

1 January - 31 December 2016

Discoveries to benefit <mark>everyone's</mark> health

TASTE TEST

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2016 Highlights

Raising National Awareness of Research

Over half a million viewers tuned in each week to SBS-TV's insight double series.

Professor John Hopper, ATR Director, won Victoria's top prize for scientific discoveries and technological innovations that improve lives.

Fast Tracking Research

15 studies conducted in 2016, including ground breaking work in breast cancer risk factors

> 14 travel grants supporting researchers translating their work

36 Publications

Growing Our Membership

2624 twins & 30 triplets joined us this year

5792 twins approached to participate in studies

OUR LIFETIME IMPACT



Nearly 17% of Australia's twin population volunteer for studies and help to fast track research.

Twin research has contributed to break-through knowledge into major health issues including diabetes, epilepsy, breast cancer, brain ageing, bone health, autism, children's education and learning.





Our researchers collaborate in universities, hospitals and institutes Australia-wide (and globally) to generate new knowledge in priority health issues.

We translate study findings into practice, policy and evidence-based resources for our communities.





ABOUT THE ATR



The ATR is Australia's only national twin research centre of excellence and maintains one of the largest volunteer twin research registries in the world. It both undertakes and supports twin research in institutes and hospitals across Australia and globally. Twins and their families make our research possible by volunteering to be part of studies.

Based at the Melbourne School of Population and Global Health, University of Melbourne, the primary goal of the ATR is to bring twins and researchers together to undertake health research to benefit everyone.

VISION AND MISSION

Our vision is for a vibrant and unified global twin research community to improve health and medical knowledge for the benefit of all humankind.

Our mission is to generate twin research that demonstrates how new knowledge can improve health and prevent disease.

OUR VALUES ARE



Accountability

To be accountable to our members, our researchers, our supporters and each other.



Integrity

To act honestly and ethically in the way that we conduct ourselves.



Excellence

To use our expertise, energy and resources to deliver best-practice, sustainable results.



Collaboration

To facilitate connections within the twin, research and wider community to more effectively advance health and wellbeing.



Innovation

To find resourceful and inventive solutions to advance people's health and well-being.





DIRECTOR'S MESSAGE

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This year we continued our efforts to nurture the next generation of researchers.

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The Australian Twin Registry continued to make outstanding progress this year. It made significant progress towards its mission of improving health and well-being. We bring twins and researchers together to make discoveries that benefit everyone.

This progress was achieved by continuing to grow our membership base and initiating new projects in line with our research focus. The registry is currently supporting studies across a range of fields including mental health, bone health, back pain, ageing and exercise as personalised medicine.

We continued our efforts to translate research findings to the greater community including health practitioners, government and the public. This involved generating published papers and evidence-based resources to stakeholders so they understand the implications and benefits of discoveries from twin research. One of the highlights of our efforts this year was the broadcast of a special double episode of SBS-TV's national science show, Insight, showcasing twin research. The program highlighted studies in dementia, back pain, singing ability, educational development, breast cancer and the origins of chronic diseases. The program demonstrated how the powerful application of the twin study design has opened up new understandings on being able to treat, prevent and cure diseases in Australia and globally.

This year we continued our efforts to nurture the next generation of researchers. We provided training, educational workshops, mentorship and support for a number of researchers and students such as PhD student, Shuai Lui. Shuai is focusing on research into breast cancer risk factors. Epigenetics are the switches that sit above our genes, and can turn genes on and off, making us potentially more susceptible to some diseases like cancer. Shuai has been studying how epigenetics contributes to the risk of cancer and how these risk factors may develop as early as when a baby is in the mother's womb.



Looking to the future, we will be implementing a series of educational programs for researchers and statisticians on the utilisation of twin methods and statistical analysis of twin data. Next year will also see the launch of a new name, Twins Research Australia, for our organisation. We believe this new name will better reflect our purpose and expand research activities. More of our focus will be directed at bringing the research community together collaboratively, on a global scale, to optimise research advances.

Our achievements this year would not have been possible without the wonderful support we receive from twins and their families, who continue to generously volunteer their time to participate in studies. I would also like to acknowledge the support and collaborative efforts of the researchers who work with us and strive to make transformative insights to better our lives.

Mention must also be made, and thanks given to our advisory board and our small team of highly dedicated professional staff for their commitment to ensuring the ATR's continued success.

On a personal note, this year I was honoured to receive the Victorian Government's Victoria Prize for Science and Innovation which recognised my research into better understanding the genetic and environmental factors in major cancers and other diseases. My heartfelt thanks go out to the twins, their families, my fellow researchers and the ATR staff who have supported me over 30 years and made my research possible.

We look forward to moving into new frontiers of research with your support.

Warm regards,

John Hopper Australian Twin Registry

OUR PROGRAMS

The Australian Twin Registry has many programs that serve our key stakeholder groups, the research and twin communities. These programs aim, through the exchange of knowledge and the development of strong collaborations, to strengthen the skills of researchers and empower the twin community through the development and dissemination of evidence-based resources, advocacy and the nurturing of community connections.

1. Research

Conduct research. The ATR undertakes research to improve health for everyone.

Enable research. The ATR collaborates with researchers to develop their studies and recruitment strategies and to connect them with interested members for the purposes of study participation. To support this the ATR maintains and continues to grow a register of twins by fostering an interest in research for the greater good, seeking to provide positive experiences and advocating for twins.

2. Knowledge Translation

Sharing knowledge. The ATR actively initiates and promotes the exchange and translation of knowledge amongst its key stakeholders, including researchers, the twin community, health professionals and policy and decision makers.

3. Building Capacity

Experts in twin research methods. The ATR advises researchers on designing twin study models, provides training opportunities for early career researchers, enables access to historical data, and recruits and facilitates twin participation.

Entrepreneurs and innovators. The ATR actively identifies opportunities to grow knowledge, pioneer new ways to undertake research for improved returns on research investment, and accelerate health knowledge.

• 4. Governance

Apply governance of the ATR in a fair, transparent and equitable manner.



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The TWIN-E study in emotion and cognition

PI: Dr Justine Gatt, Prof Peter Schofield

The TWIN-E Emotional Wellbeing study is a large prospective study of over 1,600 monozygotic (MZ) and dizygotic (DZ) adult twins, tested on emotional and cognitive measures of neurocognitive function, autonomics, electrophysiological measures, measures of neuroimaging, as well as salivary samples for DNA.

Project goals include: Establishing the role of genetics versus environment for emotion and cognition; examining the amount of shared genetics and environment between emotion and cognition, anxiety and depression; and how specific genes and life experiences may account for these shared relationships.

Recent findings

Study results show that the common variance between each regulation strategy and adaptive functioning has both a genetic and an environmental component. Furthermore, this model demonstrates some of the same nonshared environmental influences that increase reappraisal are also related to improved negativity bias, resilience, and social/emotional intelligence. Nonshared environmental influences on reappraisal also predicted adaptive emotional functioning.

McRae, K., Rhee, S. H., Gatt, J. M., Godinez, D., Williams, L. M., Gross, J. J. (2017). Genetic and environmental influences on emotion regulation: A twin study of cognitive reappraisal and expressive suppression. *Emotion*, 17(5), 772-777.



Investigating the genetic and environmental factors contributing towards temperament in children: A study of monozygotic twins

PI: Eloise Cameron

This project is investigating how temperament develops over time, with a particular focus on the period of late childhood through to mid-adolescence. It aims to study temperament by looking at where it might be identified in the brain, and how these areas are connected to one another. It will also investigate what genetic and environmental factors might influence temperament development, particularly the influence these factors have on the brain biology of temperament.

The AUstralian Twin BACK pain (AUTBACK) study: Pilot study

PI: A/Prof Paulo Ferreira

Low back pain has a strong genetic component and affects four million people in Australia. Prevention is not yet possible because modifiable risk factors are not well established. The AUTBACK study will explore the effects of different types and amounts of physical activity on low back pain. Results of this study will help the development of strategies to prevent low back pain.

Efficacy of a sleep quality intervention in people with chronic low back pain controlling for genetics: A preliminary randomised co-twin controlled trial

PI: A/Prof Paulo Ferreira

This study is investigating the value of a sleep quality program in people with low back pain and insomnia. Researchers will assess the effects of the six-week online cognitive behavior therapy (CBT) program which aims to improve pain selfefficacy and patients' specific levels of function.

Pinheiro, M., Ho, K., Ferreira, M., Refshauge, K., Grunstein, R., Hopper, J., Maher, C., ... Ferreira, P. (2016). Efficacy of a Sleep Quality Intervention in People With Low Back Pain: Protocol for a Feasibility Randomized Co-Twin Controlled Trial. *Twin Research and Human Genetics*, 19(5), 492–501.



A twin study of the NAPLAN

PI: Dr William Coventry, Prof Brian Byrne

Researchers are using the NAPLAN results of twins, other multiples and siblings to help identify the genetic and environmental factors that influence how well a child performs in these tests. This information will be important for developing advice about measures that parents and educational authorities can take to help all children reach their full potentials in school; and to inform policy-makers about the roles of schools and teachers in children's rates of academic progress.

Findings

Results showed that reading followed a compensatory growth pattern, largely due to genetic effects, while variation in growth in other literacy domains were predominantly due to environmental influences. Genes and the shared environment influenced growth in numeracy for girls, while for boys it was influenced by the shared and unique environment. These results suggest that individual differences in growth of reading are primarily due to a genetically influenced developmental delay in the acquisition of necessary skills, while environmental influences, perhaps including different schools or teachers, are more important for the other domains.

Grasby, K., Coventry, W., Byrne, B., Olson, R. & Medland, S. (2016). Genetic and Environmental Influences on Literacy and Numeracy Performance in Australian School Children in Grades 3, 5, 7, and 9. *Behavior Genetics*, 46(4), 627–648.

Grasby, K. and Coventry, W. (2016). Longitudinal Stability and Growth in Literacy and Numeracy in Australian School Students. *Behavior Genetics*, 46(5), 649–664.

Livingstone, L., Coventry, W., Corley, R., Willcutt, E., Samuelsson, S., Olson, R., Byrne, B. (2016). Does the Environment Have an Enduring Effect on ADHD? A Longitudinal Study of Monozygotic Twin Differences in Children. *Journal of Abnormal Child Psychology*, 44(8), 1487-1501.



Towards exercise as personalised medicine: Is non-response to exercise generic, genetic or modality dependent

PI: Prof Daniel Green

Exercise training improves health and well-being, quality of life, depression and anxiety and prevents or reduces the impact of many diseases. However, it seems that not all individuals benefit from exercise programs to the same degree and some people do not respond to exercise at all. The main aim of this study is to work out whether a person's genetic make-up influences how they respond to exercise training. Ultimately, this research will be vitally important in helping scientists to individualise the prescription of exercise and to ensure that everyone gets the best possible benefit from exercising.

Genetics and personality as predictors of the extent to which we join, and identify with, groups.

PI: Dr Fiona Barlow

We now know that the social groups that we are born into and join are associated with how healthy we are, how happy we are and how long we live. However, some important questions are unanswered or underexplored, including:

- Why some people happily join multiple groups, while others fail to find even one to which they feel they belong
- Why some people really feel that they "fit in" with groups, while others feel "alone in the crowd"
- Why some people enthusiastically join diverse groups, while others "stick to their own"

This project seeks to find the first answers to these questions. Combining classic personality, psychological and social psychological approaches with a behavioural genetics understanding of heritability, the study aims to identify genetic, personality and environmental factors that influence people to join or reject groups.



WATES study - Extended Twins Eye Study in Tasmania (TEST)

PI: Prof David Mackey, Dr Alex Hewitt, Dr Stuart Macgregor

This Western Australian Twins Eye Study is an extension to the Twins Eye Study in Tasmania. The study aims to learn more about the heritability, genetic influences and environmental factors associated with ocular measurements and eye diseases. The Twins Eye Study in Tasmania has been running for over a decade and is among those that have led to the identification of several genes that may predispose some individuals to certain diseases such as myopia and glaucoma.

Mackey, D. A., MacKinnon, J. R., Brown, S. A., Kearns, L. S., Ruddle, J. B., Sanfilippo, P. G., ... Hewitt, A. W. (2009). Twins Eye Study in Tasmania (TEST): Rationale and Methodology to Recruit and Examine Twins. *Twin Research and Human Genetics: The Official Journal of the International Society for Twin Studies*, 12(5), 10.1375/twin.12.5.441. http://doi.org/10.1375/twin.12.5.441

OATS amyloid imaging project

PI: Prof Perminder Sachdev

A known predictor in brain ageing is 'plaques' which contain the amyloid protein. It is not known however what causes these plaques or who is at risk of developing them. This study aims to take brain scans (NAV-PET scans) to determine whether these plaques have a genetic component and how they relate to performance in memory and thinking.

Recent findings

White matter hyperintensities (WMH) are signal changes in the white matter seen on magnetic resonance imaging which are common in otherwise healthy middleaged and elderly individuals. Those seen in asymptomatic older individuals are likely to be associated with hypertension, diabetes mellitus and coronary artery disease. White matter hyperintensities have a strong genetic influence but this is not uniform through the brain, being higher for deep than periventricular WMH and in the cerebral regions. The genetic influence is higher in women, and there is an age-related decline, most markedly for deep WMH. The data suggest some heterogeneity in the pathogenesis of WMH for different brain regions and for men and women.

Sachdev, P. S., Thalamuthu, A., Mather, K.A., Ames, D., Wright, M.J., Wen, W., OATS Collaborative Research Team. (2016). White Matter Hyperintensities Are Under Strong Genetic Influence. *Stroke*, 47(6): 1422-1428.



Effect of menopause on bone structure in twins

PI: Dr Ego Seeman

The purpose of the study is to understand how bone structure changes during menopause and how hormonal factors contribute to bone loss and bone fragility. Postmenopausal twin pairs and women with forearm fractures will be studied prospectively in premenopausal, perimenopausal.

Recent findings

We infer that middle-aged women differ in their bone microarchitecture and remodeling markers more due to differences in their genetic factors than due to differences in their environment.

Bjørnerem, Å., Bui, M., Wang, X., Ghasem-Zadeh, A., Hopper, J., Zebaze, R., and Seeman, E. (2015). Genetic and environmental variances of bone microarchitecture and bone remodeling markers: a twin study. *Journal of Bone and Mineral Research*, 30(3): 519-527.

Diabetes and dementia

PI: Prof Velandai Srikanth

Type 2 diabetes mellitus is associated with a two-fold increased risk of dementia. The reasons for this are unclear. This study aims to examine glucose use in the brain and how this may contribute to the risk of dementia. The researchers would like to compare twins with and without diabetes to understand if there are any differences in brain structure and function.



Recent findings

Type 2 diabetes was associated with significantly reduced activation in left hemisphere temporoparietal regions including angular gyrus, supramarginal gyrus and middle temporal gyrus and significantly increased activation in bilateral posteriorly distributed regions. Differences in activation were more pronounced among MZ pairs, with MZ individuals with diabetes also displaying greater frontal activation. These results provide evidence for preclinical memoryrelated neuronal dysfunction in type 2 diabetes. They support the search for modifiable later-life environmental factors or epigenetic mechanisms linking type 2 diabetes and cognitive decline.

Wood, A. G., Chen, J., Moran, C., Phan, T., Beare, R., Cooper, K., ... Srikanth V. (2016). Brain Activation during Memory Encoding in Type 2 Diabetes Mellitus: A Discordant Twin Pair Study. *Journal of Diabetes Research:* doi: 10.1155/2016/3978428.

Genetics of Epilepsy: A Twin Approach to Complex and Non-Traditional Inheritance Patterns

PI: A/Prof Lata Vadlamudi

This research study is investigating the role of epigenetics in epilepsy. Although our genes are very important in making us who we are, they are only a part of the picture – as our genes are influenced by environmental factors. This research hopes to improve understanding into the causes of epilepsy, which could then improve treatment options in the future.

Enabling Research

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The ATR continues to enable research through its collaborations with researchers, both nationally and internationally, to recruit twins to participate in health-related studies.

ATR enabled studies are classified into three areas:

Those in the initial stages of planning and development;

Those involved in active recruitment;

Post-recruitment and statistical support.

There were 81 active and ongoing studies utilising ATR services and/or involving ATR members in 2016. This includes the active processing of seven expressions of interests (EOIs) for new research and three new research applications (as a result of approved EOIs) throughout the year. In total, there were 11 active recruiting studies with participants in 2016. The ATR also provided ad hoc support to a further 63 studies in varying stages of study development, data collection, data analysis and writing up.

Table of the number of studies supported by ATR in 2016 by status

Study Status	Number
Active Application (EOIs, Full Application, Protocol Change)	7
Recruiting	11
Data Collection/Data Analysis	33
De-identified Data Analysis	4
Writing Up/Publishing	26
Total	81

Table 1 Study Status

Study invitations	Mail outs to prospective participants for individual studies are a core component of the Registry's daily operations. Scheduling of mail outs and the total number of approaches sent is dependent on the requirements of each research project. During 2016, 34 mail outs were conducted and a total of 3,694 study invitations were sent.
	were sent.

Reminders

In 2016 there were 3,728 study reminders sent to Registry members. This figure is less than the 19,311 reminders for 2015 as we approached significantly less people with invitations in 2016 than in previous years.

The Health and Lifestyle Questionnaire The Health and Lifestyle Questionnaire (HLQ) was launched in 2014, in part, to better describe the ATR membership through the publication of summary statistics to both the twin and the researcher communities. These statistics include zygosity, age, gestation term and medical conditions.



Figure 1. Sex and zygosity of HLQ participants

The HLQ enables identification of potential participants for specific research studies to reduce costs to researchers and unnecessary approaches to ineligible ATR members. It also enhances fast-track research by providing de-identified data to researchers for ethically approved research analyses. Of those invited this year, 198 pairs and 95 individuals accepted the invitation to take part in the adult questionnaire; 510 pairs (parents of pairs) accepted the invitation to take part in the junior questionnaire. In 2016 two research groups conducted studies using this de-identified data. In addition three studies utilised information from the questionnaire to conduct targeted recruitment.

Publications

An important measure of the output of the ATR is the number of publications arising from studies supported by the facility. In 2016, the ATR recorded 29 peer-reviewed journal articles and seven conference proceedings, for a total of 36 publications, (**Figure 2**). There have been more than 700 publications in the last 15 years. The ATR's CRE goal is to increase annual twin publications by 20 percent. The list of all 2016 publications can be found in the Appendix.



Fig 2. Published Peer-Reviewed Journal Articles Australian Twin Registry

The Registry

MEMBERSHIP



The ATR volunteer members are an integral part of the organisation, and management of the membership is a core component of its function.

The ATR undertakes a wide range of activities to keep its membership active and engaged. These include providing opportunities to update details on the website and through the E-News; following up return to sender mailed communication through study approaches; the printed newsletter and via phone calls to the twins' or second and third contacts.

Two notable areas of engagement in 2016 were in the areas of social media and collaboration with the SBS-TV Insight program.

Social Media Engagement

The ATR's social media channels include Instagram (856 followers), Twitter (1,282 followers), Facebook (9,162 followers) and a LinkedIn profile. Of these, Facebook is our strongest social media channel in terms of followers, reach and engagement. Favorite Facebook posts included: This special relationship of twins should be fostered, not forced apart (reach 20,200); Australia's oldest twins (reach 34,400); promoting SBS-TV's *Insight* episode on twins (reach 38,700); and intrusive comments about twins from non-twins (reach 58,500).

Table 2. ATR Facebook reach

Facebook Stats 1/1/16 - 31/12/16		
Reach of 711.000	The number of people who were served any activity from our page including our posts, posts to our page by other people, mentions and checkins.	
Facebook followers increased from 8,376 to 9,162	90% of followers are women Overall 26% aged 25-34 38% aged 35-44 15% aged 45-54	

Engagement – 60,000 post clicks; 24,220 reactions, comments and shares

SBS Insight Twin Special

Tuesday the 15th and 22nd March 2016 saw the airing of a special two part series on SBS Insight, looking at the valuable role that twins play in helping us understand more about health and disease.

The first episode featured the latest findings on the heritability of traits like learning ability, self-esteem, political views, religious beliefs, risk-taking, humour, happiness levels and singing talent, just to name a few. The second part delved more into the latest twin research findings on health and disease.

Nine of the ATR's researchers were guest panellists on the two episodes and discussed how twins 'open up new doors' to teach us more about what it is to be human.

Twins Craig and Brenton Gurney were two of the many ATR members who appeared on the show with a fascinating story to tell. Brenton reported that "If I wasn't on the twin registry I probably wouldn't be here" after his twin, who had been suffering headaches convinced him to join a study that involved an MRI. Incredibly, their participation resulted in the discovery of a brain tumour in Brenton's skull base. Brenton, who had not experienced any symptoms, credits Craig's headaches – and their subsequent study involvement – with saving his life.

Not all twins receive a direct benefit from their research participation, but instead are assured that their input has immeasurable value in helping researchers learn more about conditions from diabetes to autism and eating disorders. This is something that resonated with many Insight viewers who were twins or parents of twins, with the ATR receiving nearly 400 new registrations and a further 100 expressions of interest in study involvement from existing members following the screening.

DESCRIBING OUR MEMBERS

The ATR maintains an up-to-date register of twins and HOMs (or in the case of twins and HOMs under the age of 18, their parents) willing to consider involvement in scientific studies.

> The ATR continues to update and improve internal database processes and mechanisms to better assist staff in providing a cost effective and efficient service to twins and researchers.

> Twins and Higher Order Multiples (HOMs), including triplets, quadruplets and quintuplets of all ages, sex combinations and zygosity are eligible to enrol with the ATR.

In 2016, the database held data on 94,166 individuals representing 46,405 twin pairs and 449 HOM sets. Of these, 25% were juniors (<18yrs) and 75% adults (>=18 years); 42% were same sex female pairs, 33% same sex male pairs and 25% opposite sex pairs. In addition, 39% were identical (MZ), 57% non-identical (DZ) and 4% unsure of their zygosity. Members reside in all states and territories of Australia. In addition, 154 twin pairs identify as Aboriginal and/or Torres Strait Islander. This includes 107 junior pairs and 47 adult pairs; 67 identical pairs, 81 non-identical pairs and 6 of unknown zygosity.

Members of the ATR are recorded under a specific status, depending on the currency of their contact details and individual preference for involvement in research activities. The current status of members of the ATR is summarised in Table 3.

7	T1/T2 Status	Active	Inactive	Deceased	Lost/ Pending	Total
	Active	34786	508	468	1612	37374
	Inactive	533	1602	288	178	2601
M	Deceased	429	247	599	70	1345
	Lost/Pending	1561	110	73	3341	5085
	Total	37309	2467	1428	5201	46405

Table 3. Twin Pair Registration Status

Twin 1

Active Twin Pairs by Sex and Zygosity

The current numbers of active twin pairs by sex and zygosity are shown in **Figure 3**. It includes individuals in a pair who have a registration status of: Active, Newsletter or Questionnaire.



MZ = monozygotic, DZ = dizygotic, UK = unknown



Distribution of Active Twin Pairs

The distribution of active twin pairs by location is shown in **Figure 5** together with the overall distribution of the Australian population by state and territory (as reported by the Australian Bureau of Statistics in 2016) in **Figure 4**. Comparison of the two graphs shows that most populated states are also the states where most active ATR members reside.







Figure 5. Distribution of Active Twin Pairs by State 2016

Recruitment Continuous recruitment of new members is vital to ensure the future viability of the ATR. In the reporting period 1 January 2016 to 31 December 2016 the ATR recruited a total of 1,385 twin and hom sets, an increase from 2015 (1,250 twin and hom sets recruited).

Sources

The internet continues to be the dominant means of registration (73%), increasing by about 10% from 2015, with 25% recruited by phone (decreasing by about 10% from 2015) and 1% via mail. **Figure 6** shows the top six recruitment sources in 2016.



Figure 6. Registration Ascertainment 2016: Major Sources

Age Range

As shown by **Figure 7** the majority of new members (79%) enrolled with the ATR during the reporting period were aged 0-9 years. This is consistent with the previous 20 years.

Figure 7. Number of Active Twin and Triplet Sets Registered in 2016 Shown by Age Range

* includes individuals who are alive and all individuals in the pair have a registration status of: Active, Newsletter, Questionnaire



New Registrations by Year

The numbers of new registrations by year since 2004 are represented in Figure 8.

Figure 8. Number of New Twin and HOM Sets Registered with ATR by Year Since 2004.

* 2012 peak: Merge of Western Australian Twin Registry with Australian Twin Registry



Record Updates

The Registry also undertakes proactive tracing of its members, this is an ongoing and important maintenance activity and ensures that the Registry remains viable. In 2016 the ATR maintained accurate information on 83% of its members. All prior addresses and any actions taken to trace members are recorded on the ATR database.

In 2016, a total of 4,819 individual twin and other contacts (i.e. parent or secondary carer) member records were updated in the ATR database. This includes instances where an individual record, address information or phone number/email address has been edited; and those records followed-up due to receipt of a Return to Sender (RTS); and routine tracing or contact after a study approach has been sent. A count of all individual records updated yearly since 2010 is shown in **Figure 9**.



Fig. 9 Individual Records Updated Per Year (2010-2016)









KNOWLEDGE EXCHANGE

Knowledge exchange and translation at the ATR is a dynamic process. It involves researchers, community and stakeholders being actively involved throughout all stages of our operations, research and education programs.

We do this by:

Translating study findings back to key stakeholders to influence policy and practice.

Translating our knowledge in twin research and registry management to the research community through capacity building initiatives and materials, publications and mentoring.

Providing evidence-based resources to our twin communities.

Communications The ATR continued online initiatives such as study progress reports to individual participants and the quarterly E-news to provide feedback on overall study findings and activities to ATR members.

The E-News plays an important role in raising awareness of the role of twins in research and translating research findings to the wider community. In 2016, four E-news editions were sent to ATR members and four E-news editions were sent to researchers.

Media: Newspapers, Magazines, TV, Radio and Online

In 2016, considerable media coverage and events were achieved by the ATR. There were 29 press articles in newspapers, magazines, TV, radio and other media including online. A major highlight was the SBS-TV Insight two part series, looking at what the latest research about twins can tell us about ourselves. Over 500,000 viewers tuned in for each episode, making it one of the most popular Insight programs to date.



Pregnancy Booklet

The ATR Twin Pregnancy Booklet is an evidence-based resource freely available to families expecting twins. Developed in conjunction with health professionals and twin parents, the booklet contains helpful information about twins, what to expect during pregnancy and when the babies come home.

Currently the ATR sends out over a thousand booklets annually to expectant and new parents all over Australia, and demand for this comprehensive resource is growing significantly each year.

A systematic review of the booklet is planned for 2017, as a feasibility assessment on providing the information as part of a broader twin pregnancy mobile app.



Building Research Capacity



In 2016 a comprehensive education strategy was developed and aimed at further developing the research community's capability and capacity to conduct twin studies, thus expanding the capacity for future twin research. This strategy is to be implemented over the next two years.

The overall purpose will be to:

Raise awareness of twin methods and the value they deliver across the general research community; and of the services and resources offered by the ATR to enable the utilisation of twin methods (with explanations about how the ATR can support research and researchers) including:

General services - recruitment, basic twin study design etc. and

Specialised services – highly customised twin study design, data storage/custodianship, statistical analysis, translation

Educate interested parties by:

Supporting and supervising PhD scholarships for work related to twin research

Supporting Masters of Public Health (MPH) research projects

Conducting seminars and short courses

Including twin methods in MPH courses

Developing online resources

Integrate and foster the development of novel ways to address twin research in new frontiers of genomic, big data and epigenetic technology to targeted research audiences.

SUPERVISION OF PHD AND MPH STUDENTS

PhD Students	Shuai Li, University of Melbourne (supervised by John Hopper)			
	Lucas Ferreira , University of Melbourne (supervised by John Hopper, Louisa Flanders)			
	Mihiri Silva (supervised by Katrina Scurrah, Jeff Craig, Nicky Kilpatrick and David Manton)			
	Eloise Cameron (supervised by Katrina Scurrah, Jeff Craig and Marc Seal)			
MPH Students	Siyao Li, University of Melbourne (supervised by Katrina Scurrah)			
	Suitana Hazia, University of Melbourne (supervised by Katrina Scurrah)			

KEY RESEARCH CAPACITY BUILDING ACTIVITIES CONDUCTED IN 2016 INCLUDE:

International Research and Research Training Fund (IRRTF)

This IRRTF grant, funded by the University of Melbourne, supports the project titled "A collaboration to establish the Brazilian Twin Registry based on the Australian Twin Registry." This project started in 2015 and aims to support the knowledge exchange between the two twin registries; and provides the means for the future sustainability of both organisations through international scientific collaboration.

The achievements of the IRRTF grant in 2016 include:

A workshop and meetings in June between researchers from the ATR, BTR and other international collaborators in Melbourne. These activities generated a draft proposal for a twin study to be submitted to the National Institutes of Health (USA) and FAPESP (Brazil) in early 2018.

Training of BTR coordinators across the many aspects involved in operating a twin registry such as, study coordination, data management, statistical analysis and recruitment of twins for new studies.

Participation of BTR coordinators in the ATR strategic workshop to assure alignment between the two organisations.

Presentations and networking of Brazilian and Australian researchers in the International Congress of Twin Studies 2016 in Brisbane.

Plans for 2017 include a roadshow of researchers in Brazil from the BTR and the ATR. This will include presentations and meetings aimed at discussing the benefits of twin studies and new studies involving Brazilian twins and new collaborators. The IRRTF grant will also fund the development of Worldwide Twins, a web-based platform to facilitate new collaborations within the International Network of Twin Registries under the leadership of Brazilian and Australian researchers.

TWINS SEMINAR AND WORKSHOP

Why and How Twins Studies are Valuable for Your Research



The Australian Twin Registry held a workshop in September to promote and educate researchers on the power of the twin model as well as support current twin researchers.

The day was divided into two sessions: the first focused on the strengths and applicability of a variety of twin study designs and the resources available to collect and analyse data from twins. The second session was a workshop presenting twin research studies in progress, to those currently involved, or interested in twin research.

Both sessions proved to be extremely valuable to new and existing researchers attending the event. Approximately 60 participants attended the introductory seminar and/or workshop, including presenters and staff. Popular sessions included the statistical analysis and qualitative research segments. Featured speakers included Karin Magnusson, Department of Rheumatology, Diakonhjemmet Hospital, Oslo, Norway; and Richard Saffery, Murdoch Children's Research Institute. Participants travelled from around Melbourne and interstate.



TRAVEL GRANTS



The Travel Grant Scheme aims to encourage the growth and development of twin research in Australia by:

Offering financial assistance to Australian researchers to attend ATR workshops and events and thus support their training and development in the methodology and practice of studies involving twins.

Presenting and promoting ATR based twin research studies at scientific conferences.

Grants in 2016 were awarded to support travel to general research conferences in May and to the Australian Twin Registry workshop in September.

There were a large number of applicants who applied for funding to assist their travel to national and international research conferences. Congratulations to the following successful recipients:

Dr Teresa Lee, Neuropsychiatric Institute and Centre for Healthy Brain Ageing, University of New South Wales

Amabile Borges Dario, Discipline of Physiotherapy, The University of Sydney

Anita Barros Carlos de Amorim, Discipline of Physiotherapy, The University of Sydney

Liang-Dar (Daniel) Hwang, Genetic Epidemiology Group, QIMR Berghofer Medical Research Institute

Andrew Costanzo, School of Exercise and Nutrition Sciences, Deakin University

Marina de Barros Pinheiro, Discipline of Physiotherapy,

The University of Sydney

Shuai Li, Centre of Epidemiology and Biostatistics, The University of Melbourne

Theresa Donnelly, Pain Research Unit, Department of Pain and Palliative Care, Sydney Children's Hospital

Dr Justine Gatt, School of Psychology, UNSW and Neuroscience Research Australia

Reece Lavender, School of Behavioural, Cognitive and Social Sciences, University of New England

Luisa Livingstone, School of Behavioural, Cognitive and Social Sciences, University of New England

Dr Yuk Jing (Jane) Loke, Early Life Epigenetics, Murdoch Children's Research Institute

Dr Xiaofang Wang, Departments of Endocrinology and Medicine, Austin Health, The University of Melbourne

Channa Marsh, School of Sports Science, Exercise and Health, The University of Western Australia

Personal story Channa Marsh, School of Sports Science, Exercise and Health, The University of Western Australia

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I would like to thank ACETR for their financial assistance which allowed me to attend the ATR seminar "*Why and how twin studies are valuable for your research*" held on 13th September 2016, in Melbourne, Australia.... My PhD research involves myself being "thrown in the deep end", utilising identical and fraternal twins to assess the heritability of certain health responses as a result of exercise. The seminar catered for everyone interested in twin research covering topics from zygosity, why twin studies are so valuable, types of twin studies and why each is important, twin statistics and everything in between. ... Walking away from this seminar, I was delighted to know that there were experts from the ATR there to help me along every step of the way as they were very welcoming and passionate about twin research.

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Our People



The Australian Twin Registry's system of governance ensures accountability, fairness and transparency with all its stakeholders.

TRA comprises a leadership team of a Director, Deputy Directors, Chief Investigators and Associate Directors from institutes around Australia, and is overseen by an Advisory Board. We are supported by a team of passionate staff and administered by The University of Melbourne.

Advisory Board	Mr Vincent Pollaers, Chair, Advisory Board			
Members	 Dr Paul Jelfs, Australian Bureau of Statistics, Australian Capital Territory A/Professor Paul Lancaster, University of Sydney, Honorary Associate Professor Prof Margaret Otlowski, University of Tasmania Mrs Karen Willetts, AMBA Representative, New South Wales 			
	Ms Sue Carrick, Twin Representative, New South Wales			
Chief Investigators	Professor John Hopper, ATR Director, University of Melbourne			
	Associate Professor Jeffrey Craig, ATR Deputy Director,			
	Murdoch Children's Research Institute			
	Professor David Mackey, University of Western Australia			
	Professor Stephen Simpson, University of Sydney			
	Professor Brian Byrne, The University of New England			
	Associate Professor Paulo Ferreira, University of Sydney			
	Ms Susan Carrick, Charles Perkins Centre, University of Sydney			



The Chief Investigators are supported by Associate Investigators who bring additional skills and expertise, such as being a twin or parent of twins, corporate management, expertise in legal and ethical matters, policy and research translation, molecular epidemiology, obstetrics and perinatal data.

Associate Investigators

Professor Grant Townsend, dental health
Professor Elizabeth Sullivan, perinatal/maternal health
Professor Richard Saffery, molecular & cellular biology
Professor Brian Oldenburg, health policy
Professor Margaret Otlowski, health law
Karen Willetts, parent of twins
Professor Mark Umstad, obstetrics & perinatal data
Vince Pollaers, corporate management

Staff

John Hopper, Director Jeff Craig, Deputy director Kate Murphy, ATR Manager Jenny Boadle, ATR Study coordinator Lynette Walker, Marketing officer Shaie O'Brien, Project support officer Doug Sedunary, Graphic designer Janine Lam, Project support & administration Tessa Cutler, Research assistant Sally Savi, phone support for research studies Jodie Lipman, phone support for research studies and administration Lucas Ferreira, Research assistant Sue Carrick, Charles Perkins Centre twin node

STAKEHOLDER SATISFACTION REPORT:

Research Services



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It is always a pleasure to work with the ATR. I frequently comment to colleagues that it is one of the most wellrun, professional, and inspiring organizations I know of in the world of scientific research.

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Beauty and the Eye of the Beholder Jeremy Wilmer, Psychology Department, Wellesley College, Wellesley, Massachusetts The 2016 Annual Researcher Satisfaction survey is administered each year as part of the Annual Progress Report submitted by researchers. This questionnaire provides feedback to the ATR on their services to twin researchers, and an opportunity to improve on these services where possible.

The survey requests feedback relating to the previous 12 months on:

The researcher's overall satisfaction with communication with the ATR;

The researcher's overall satisfaction with the services that the ATR provided; and

The value of the contribution that the ATR made to the overall research project

Responses are recorded as:

1 - Very Dissatisfied / 2 - Dissatisfied / 3 - Neutral / 4 - Satisfied /

5 - Very Satisfied

The ATR received feedback from 35 research groups for 2016. There was a slight increase in researchers reporting they were 'very satisfied' with ATR services. Overall, researchers were again very satisfied with the contribution provided by the ATR and also the communication and service the ATR provided.

Figure 10. Overall Satisfaction Scores from Researchers: Evaluating communication, services and overall contribution provided by the Registry.



Funding



The Australian Twin Registry is funded by a Centre of Research Excellence Grant (2015-2019) from the National Health and Medical Research Council. In addition the ATR is reimbursed by external research groups for the costs involved in study development, recruitment and analysis.

Generosity of the Twin Community

The Australian Twin Registry's Annual Appeal resulted in 97 donations from our generous twin community. Like most medical research initiatives, we rely on funding sources other than government to continue our vital services and support the next generation of researchers. Going forward there are still powerful insights twin research can help us understand about how we can lead healthier and happier lives.

Gifts and Bequests

Gifts and bequests in a person's Will are ways ATR supporters can make a real difference into the future of Australians. If you have any questions or comments, please call our 1800 037 021 or email jboadle@unimelb.edu.au



Conception to birth

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Ageing

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CODATwins project: 26 twin cohorts

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