

Annual Report

1 January - 31 December 2012



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EXECUTIVE SUMMARY

Welcome to the 2012 Annual Report of the Australian Twin Registry (ATR)

This report summarizes the major achievements, activities and research developments of the Registry in the past year.

The 2012 reporting period coincides with the third year of the renewed Enabling Grant (2010 – 2014) from the National Health and Medical Research Council (NHMRC) that funds the ATR.

The ATR's Vision is to ***“realise the full potential of research involving twins to improve the health and wellbeing of all Australians”*** and in 2012 the ATR made significant progress towards achieving this vision. Following below is a summary of the 2012 highlights and achievements:

Highlights and Achievements for 2012

- ATR Membership numbers grew, exceeding the goal set in the Enabling Grant, with 3,259 new sets of twins and triplets registered in 2012.

A large number of new members were registered as a result of collaboration between the ATR and the Western Australian Twin Registry (WATR). Twin registrations were also bolstered following an initiative where expecting parents of twins were offered a free Twin Pregnancy Booklet that provides helpful information.

- The ATR recruited for 12 studies in 2012, 4 of which were completely new, looking at health issues from growing pains, bone health, cervical cancer and mental wellbeing. This resulted in 16,591 approaches to ATR members to participate in research.
- The research benefits enabled by the ATR were significant, with 110 peer-reviewed articles based on ATR-related studies published, as well as 1 book, 3 book chapters and 22 abstracts and posters.
- Throughout the year the ATR generated significant media coverage involving twins that highlighted and reinforced the importance and contribution of medical research to society. An ATR enabled twin study conducted at Westmead Hospital in Sydney is a great example as it generated coverage by the major television stations in prime time news slots.
- In 2012, 20,957 twin and other contacts (i.e. parent or secondary carer) records were updated. The ATR maintained accurate information on 93.4% of the members.
- The ATR co-hosted the 2012 Twins Plus Festival held on March 18th, 2012 in association with Australian Multiple Birth Association (AMBA). The Festival was the largest gathering of twin's in Australia, with over 3000 twins and family members attending. The ATR received 122 new registrations and 9 researcher groups participated at the Festival highlighting their area of twin research.
- The ATR sponsored and participated in the 2012 20th Convention of AMBA, which was held in Ivanhoe on the 28th October 2012. The ATR Club Initiative Support Grant continued to support AMBA clubs around the country.
- The Travel Grant Scheme supported a total of 17 early-career to attend relevant national and international research workshops and conferences relating to twin research.
- The ATR Director and Manager attended the 14th Congress of the International Society Twin Studies in Florence, April 1st – 4th 2012, with the Director presenting abstracts on Twin Research and Human Genetics.

- The ATR reviewed and enhanced a range and quality of services that it currently provides to the research and twin community, optimising the ATR's ability to support research that has the potential to contribute to the health and wellbeing of Australians. This was achieved by:
 - Monitoring our services to current researchers with a Quality Assurance Survey collecting feedback over 3 stages of the life span of the study;
 - Providing feedback to the twin community and the wider Australian community about research findings via the ATR's website, E-news, Facebook, Twitter, national media releases and the ATR newsletter;
 - Developing a Health and Lifestyle Questionnaire for our members to complete so as to better target twins suitable for the researcher's areas of interest (to be completed in 2013);
 - Providing a comprehensive "Working with the ATR" Guidelines and Data Transfer Agreement. This will request the return of all study data for the purpose of enabling future ethically approved studies; and
 - Continuing to lead the initiative to be part of an International Network of Twin Registries.



ATR Director, Prof. John Hopper, with the Sayer Twins, at the 2012 Twins+ Festival, Caulfield Racecourse.

Overall, 2012 has been a year of great success for the ATR in research, funding and Registry growth. The outlook for 2013 promises further progress in all these areas.

Outlook for 2013

The ATR will continue to focus on strengthening its relationships with both the research and twin communities and by doing so assist with the translation of research knowledge to society.

This will be achieved in the research community by:

- Implementing the Health and Lifestyle Questionnaire for all ATR members and making the data available for future studies;
- Implementing the collection and archiving of research data into the Ark;
- Supporting the establishment of a Brazilian Twin Registry; and
- Responding as needed to feedback from Quality Assurance Surveys.

This will be achieved in the twin community by:

- Raising the profile of the ATR through the establishment of a new international Patron, HRH Crown Princess Mary;
- Establishing the “Friends of the ATR”, a group of members that wish to participate more actively in the ATR with assistance in study feedback, volunteering in twin activities’ such as festivals, media events and fund raising opportunities;
- Distributing the 2013 Newsletter to all members; and
- Providing an information session on Twin Research by Tim Spector, a leading international twin researcher.

A key strategic priority for the ATR will be to develop a funding strategy that seeks to secure funding streams to sustain the ATR and its operations beyond the term of the existing funding grant (2014). This initiative is of utmost importance to ensure that the Australian research community has efficient and reliable access to the benefits available from the utilisation of twins in research, as enabled by the ATR.



ATR OVERVIEW

About the Australian Twin Registry

Established in 1981, the ATR is a national volunteer register of twins interested in contributing to research studies.

The primary goal of the ATR is to facilitate and support research studies involving twins.

In 2012, the ATR maintained information on 36,647 sets of twins and triplets, and supported 75 research projects in application, active recruiting, data collection or writing phase, covering a broad spectrum of health-related themes (see **Researcher Reports** in [Appendix 1](#)).

Potential for Twin Research

The ATR provides twins with the opportunity to contribute to, and make a difference in, the development of knowledge around health and medical issues that affect all Australians.

Studies involving twins play an important and unique role in developing an understanding of good health and clinical problems from a genetic and environmental perspective. Twins provide a potential resource and research tool for all medical and scientific researchers.

Twin research continues to utilise new technologies to establish the causes underlying the many health and medical issues that affect Australians. Twin studies have started to play a vital role in the emerging search for epigenetic effects produced by proteins and other molecules that bind to DNA, changing gene expression. Such epigenetic effects are a newly recognised phenomenon and have been linked to many diseases, including cancer and psychiatric disorders. Studies involving twins can significantly contribute to the investigation and identification of epigenetic factors that contribute to human disease, through their shared environments and genetics.



ATR members and identical twin sisters Brenda Barone and Julie Saunders with researchers Caroline and Eugene.

Funding

The ATR is supported by an Australian NHMRC Enabling Grant. The grant covers a 5-year period, *1 January 2010 - 31 December 2014*.

This enables the ATR to be a national resource to all researchers within Australia and worldwide.



Over 3000 Twins Plus friends and their families gathered at the 2012 Twins+ Festival, Caulfield Racecourse, March 2012.

Values

The following values guide the ATR in achieving its core functions:

Respect: The ATR conducts its operations with the fullest respect for the volunteerism of the twins and their relatives in their registration and participation; for the ATR staff in monitoring and maintaining the use of this resource; and, for the researchers in their efforts to conduct timely and relevant studies in accordance with their commitments to their funding bodies, made with the agreement of the ATR.

Leadership: The ATR will maintain and expand its role as an independent facilitator of twin studies, in training and informing researchers about the potential, design, conduct and analysis of twin studies, and in providing information about issues of relevance to twins and their relatives.

Equity of Access: The ATR undertakes its functions under the principles of equity of access by researchers irrespective of factors, such as institution, discipline, and relationship to ATR, and equity of participation of twins eligible for particular studies and activities.

Privacy and Confidentiality: The ATR holds information on registered twins in the strictest confidence and in accordance with Australian legislative requirements.

Consumer Participation: The ATR engages in and conducts activities with twins and parents of twins whenever appropriate, whether or not they are members of the ATR.

Excellence in Research: The ATR strives to enable researchers to achieve excellence in their research.

The ATR's core functions are:

Core Function 1 – The Registry

Continue the building and maintenance of an **up-to-date database** containing contact details and baseline information for twin members willing to participate in research.

Core Function 2 – Scientific Merit

Collaborate with researchers applying to the ATR to ensure that projects are of significant scientific merit and are appropriately described to ensure the ability of potential participants to provide informed consent.

Core Function 3 - Participation

Use judicious management and administration of **approach to eligible twin members** to inform them of a new research project, determine their interest in participation, and seek their permission to release their contact details to the researcher for the purpose of the project.

Core Function 4 – Value Add

Develop projects and programs to **value-add to research** in Australia.

Core Function 5 - Governance

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

THE REGISTRY

Continue the building and maintenance of an up-to-date database containing contact details and baseline information for twin members willing to participate in research

Database

The ATR maintains an up-to-date register of twins willing to consider involvement in scientific studies. This register is supported by a comprehensive database, which retrieves updated membership data to allow accurate record keeping and meaningful analysis of trends and results.

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.

Membership

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

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.

As at 31 December 2012, the database held data on 76,030 individuals representing 36,647 twin pairs and 1,230 HOMs (total number of 37,877 sets).

In 2012, 20,957 twin and other contacts (i.e. parent or secondary carer) records were updated. There were 16,591 study approaches to ATR members to participate in research. The ATR maintained accurate information on 93.4% of the members.

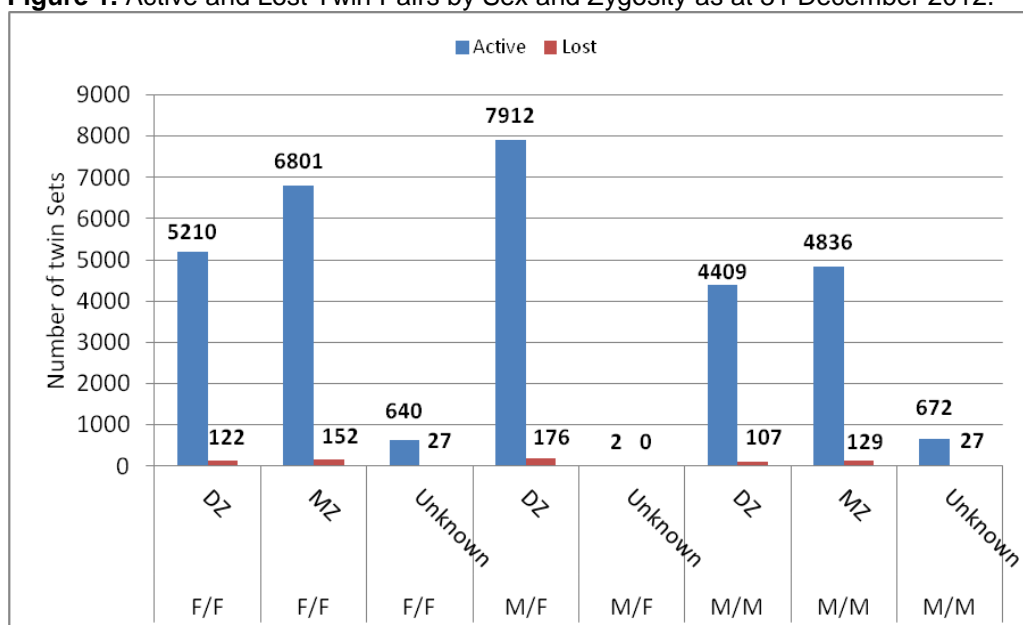
Members of the ATR are recorded under a specific status, depending on the currency of their contact details and individual preference for involvement in research activities. The majority of members enrolled in the period covered by this report (99%) are categorised as Active/Active, Active/Questionnaire and Questionnaire/Questionnaire pairs, indicating that they are willing to consider participating in research. The current status of members of the ATR is summarized in **Table 1**. A total of 72.9% twin pairs have both members active, and an additional 3.85% of members' contact details require updating (recorded as Pending). Junior members represent approximately (27%) of the entire registry, the remaining (73%) being senior members.

Table 1: Twin Pair Status Combination as of 31 December 2012. Top row details T1 (twin one) status, and left most column details T2 (twin two) status. **OS** identifies twin members who have moved overseas, but are still available for electronic surveys; **Lost OS** refers to members for whom the Registry has an unconfirmed overseas address, and it exhausted all avenues for obtaining up-to-date contact details.

T1/T2 Status	Active	Deceased	Lost	In-active	Question-naire	News-letter	OS	Pen-ding	Total
Active	26701								26701
Deceased	760	513							1273
Lost (O/S)	0	0	0	7					7
Question-naire	685	10	0	0	127				822
Newsletter	207	53	0	0	3	102			365
Lost	153	14	731	27	1	5			931
Inactive	925	424	0	1497	5	38			2889
OS	217	2	0	0	2	2	64		287
Pending	1697	53	35	103	26	29	17	1412	3372
	31345	1069	766	1634	164	176	81	1412	36647

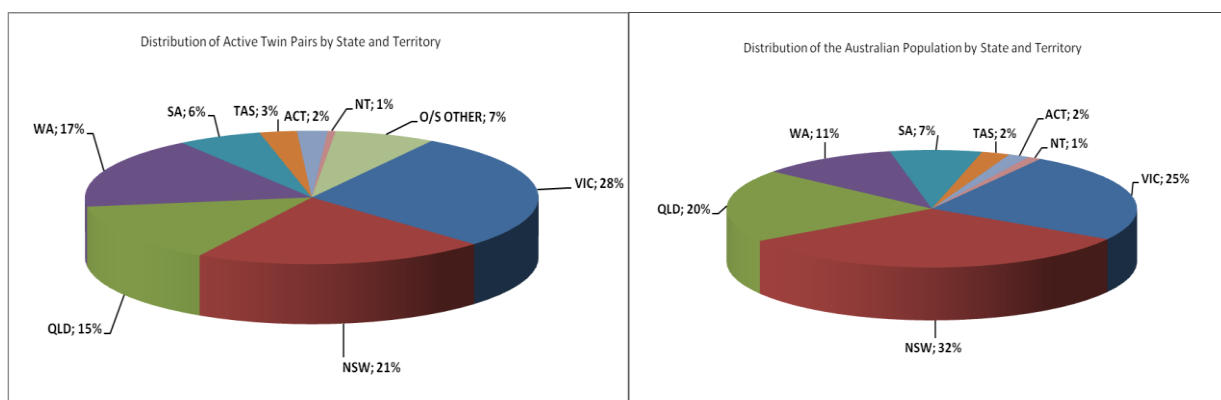
Currently, one third of the active ATR members are junior (0-19 years) and the rest of two thirds are adult. The current numbers of active and lost twin pairs by sex and zygosity are shown in **Figure 1**.

Figure 1. Active and Lost Twin Pairs by Sex and Zygosity as at 31 December 2012.



The distribution of active twin pairs by location is shown in **Figure 2**, together with the overall distribution of Australian population by State and Territory (as reported by the Australian Bureau of Statistics in 2011). Comparison of the two graphs shows that most populated states, New South Wales, Victoria and Queensland, are the same ones where most active ATR members reside.

Figure 2. Active Twin Pairs Combination by Location as at 31 December 2012 (**Left**) and overall distribution of Australians by State and Territory (**Right**). *Note: because some twins live in separate states or one twin member in a pair lives overseas, this figure captures only 25,476 of the 26,701 shown as Active/Active in Table 1.*



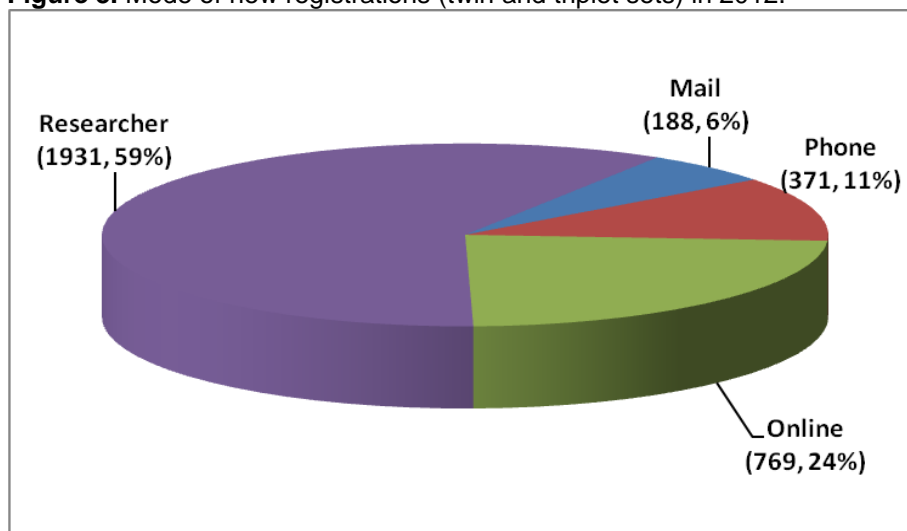
Recruitment

Continuous recruitment of new twin members is vital to ensure the future viability of the ATR. The ATR's goal is to increase membership by more than 5,000 over 5 years. In the reporting period, 1 January to 31 December 2012, the ATR added membership details on 3,173 sets of twins and 86 sets of higher order multiples (homs)¹, for a total of 3,259 sets, which exceeded the ATR's goal of recruiting 1000 members annually. The majority of new members (1,931 of

¹ Homs – higher order multiples refers to triplets, quadruplets and quintuplets.

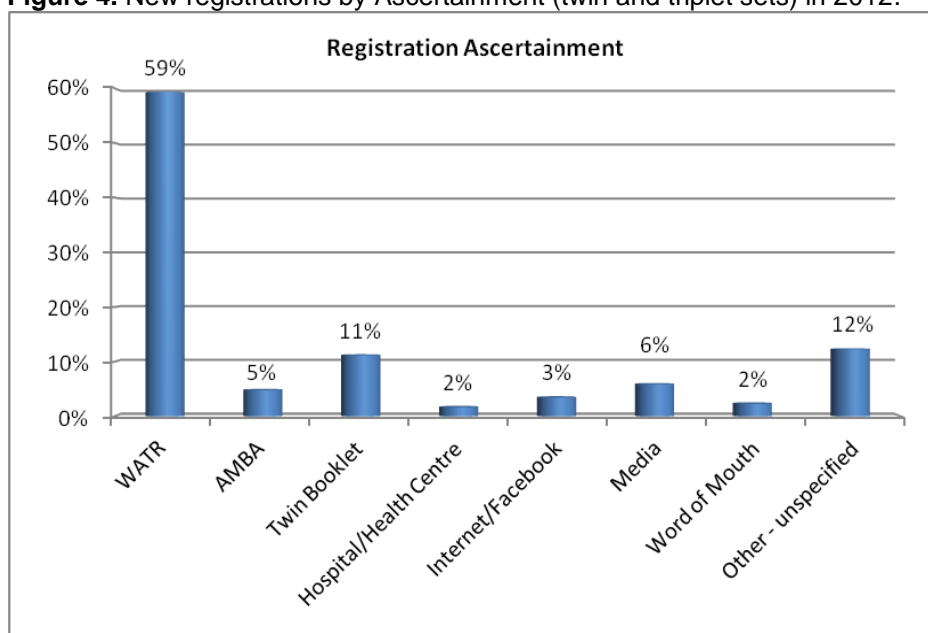
the total 3,259 sets; 59%) were registered via researcher involvement (**Figure 3**), 24% of the new registrations were completed online, 11% by phone and 6% by mail.

Figure 3. Mode of new registrations (twin and triplet sets) in 2012.



New registrations to the ATR are asked 'Where have you heard about the ATR?' From this we can ascertain that the majority of new members who registered (59%) via researcher involvement came through the Western Australian Twin Registry (WATR), while Other-unspecified accounted for 12% (**Figure 4**).

Figure 4. New registrations by Ascertainment (twin and triplet sets) in 2012.

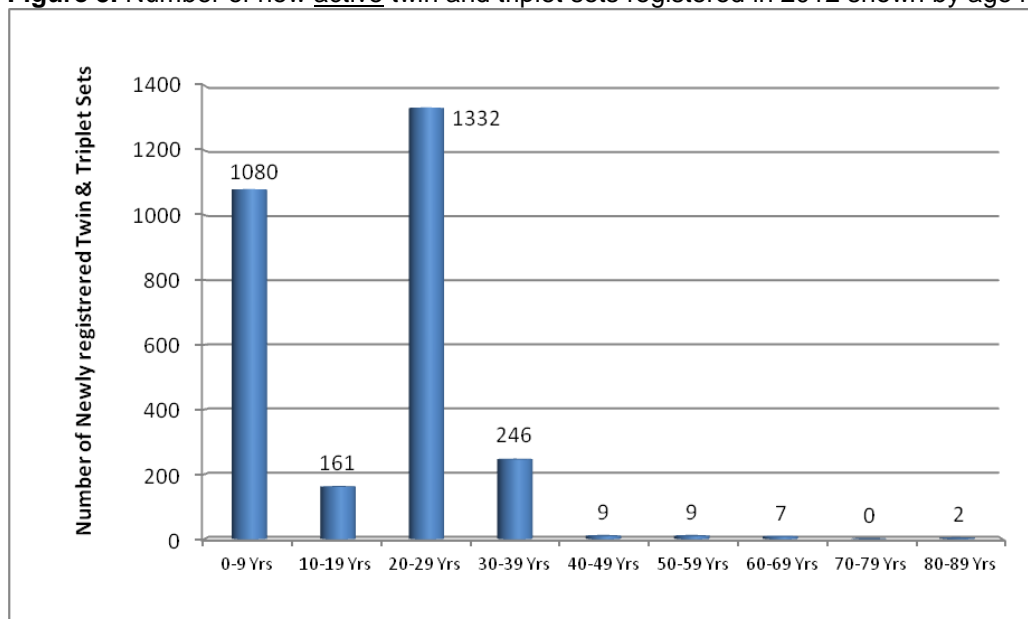


Every effort is made to ascertain where new registrations to the ATR are from, as this informs where the ATR should focus future promotion. The remaining proportion is due, in part, to the focus on promotion of the ATR through the twin pregnancy booklet provided to parents in hospital and through maternal health centres (11%), media (6%), AMBA (5%) and internet/Facebook (3%).

The majority of new members (47%; or 1462 sets of twins and 61 sets of triplets out of 3259 total) enrolling with the ATR during the reporting period were aged 20-29 years (**Figure 5**). This is somewhat of a deviation from the previous 20 years, where the 0-9 years have been the relatively consistent majority of new members (1442 sets of twins and 12 sets of triplets out of 3259 total). The 20-29 year group even surpasses the combined 0-9 and 10-19 years figure (47%; or 1526 sets of twins and triplets to 45%; or 1463 sets of twins and triplets 0-19 years). This can be partly explained to the last transfer of twins and triplets from the Western Australian

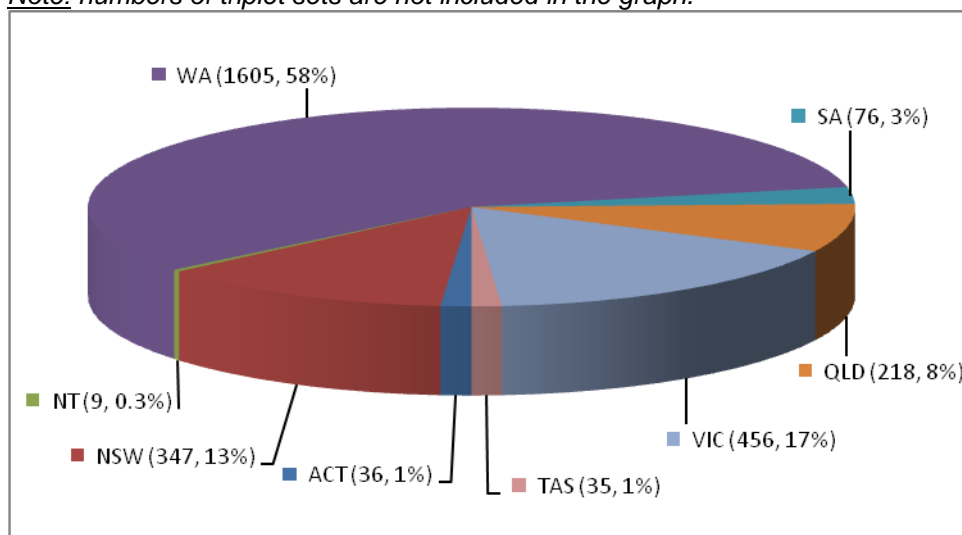
Twin Registry. An increased focus on the promotion of the ATR could also have played a factor in the increase of this age bracket. The 2013 figures should see the 0-9 years and the 10-19 years revert back to become the majority of new members.

Figure 5. Number of new active twin and triplet sets registered in 2012 shown by age range.



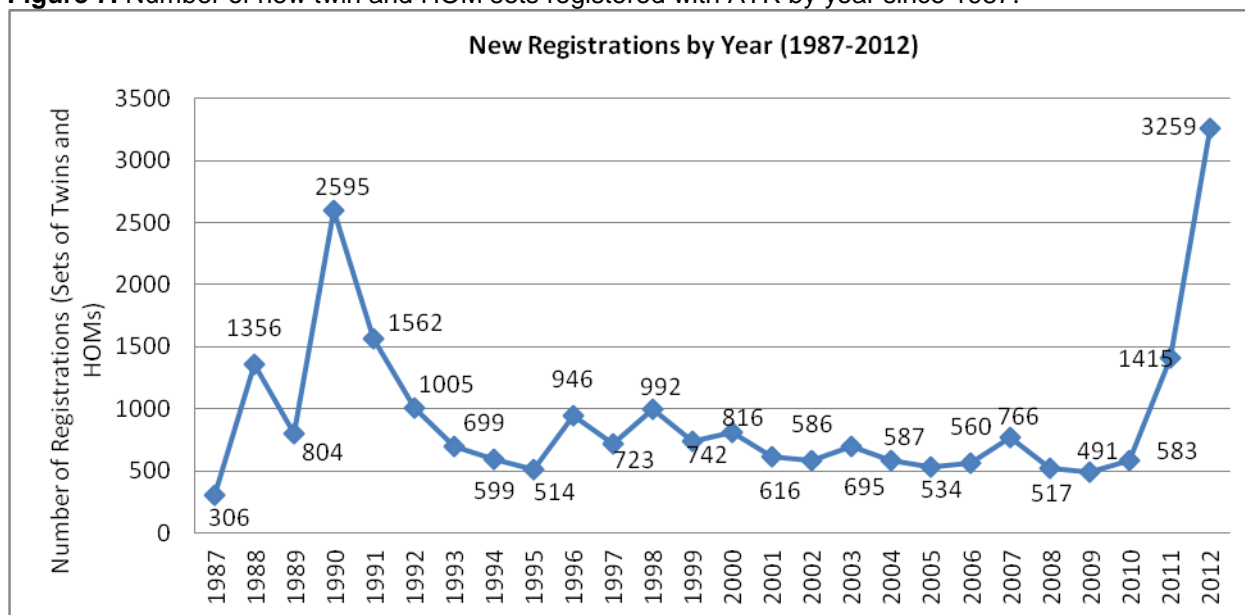
Compared with previous years, when most new registrants came from Victoria and New South Wales, in agreement with the overall population distribution in Australia, the collaboration between ATR and the Western Australian Twin Registry resulted in an increased number of new members from this state in 2012. Thus, most new members came from Western Australia (58%), followed by Victoria (17%) and New South Wales (13%) (**Figure 6**). Registrations from the remaining states were all under 10% with Queensland (8%) and South Australia (3%), followed by Tasmania and the ACT (1%). The smallest proportion of registrations came from the NT (0.3%).

Figure 6. Distribution of active twin pairs, by State or Territory, recruited during the reporting period.
Note: numbers of triplet sets are not included in the graph.



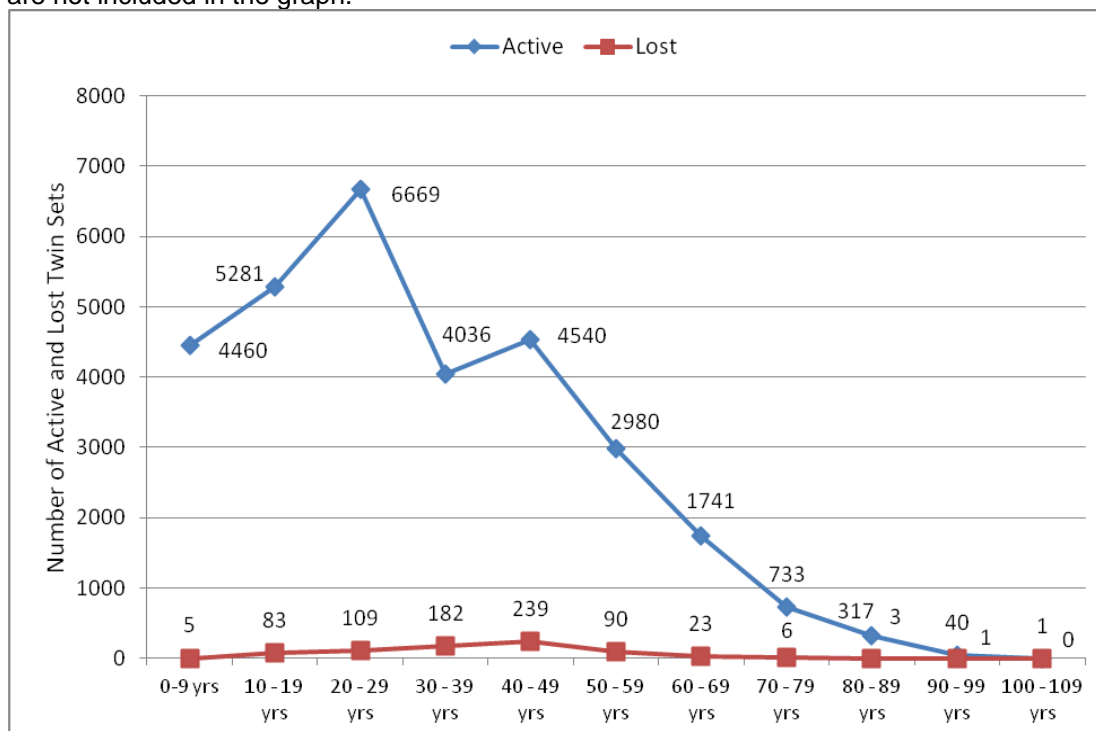
The numbers of new registrations by year since 1987 are represented in **Figure 7**. As mentioned previously, a large proportion of new registrations have come from the Western Australian Twin Registry. It is expected that the Western Australia number will reduce next year and that the greater number of new registrations will come from Victoria or New South Wales as in the past.

Figure 7. Number of new twin and HOM sets registered with ATR by year since 1987.



The distribution of active and lost pairs of twins, across the Registry, is shown relative to the age groups of members in **Figure 8**. As stated above, the anomaly with the 20-20 yrs group is the WATR members. Future years see the first three categories 0-9 years; 10-19 years and 20-29 years, as the three most consistent age groupings.

Figure 8. Active and lost twin pairs shown by age group, as at 31 December 2012. Note: data on triplets are not included in the graph.



Currency and Accuracy of Membership Data

The goal of the ATR, as outlined in the NHMRC Enabling Grant, is to maintain current information for at least 85% of the membership. This acknowledges that a proportion of twin members who have moved require tracing to update contact details.

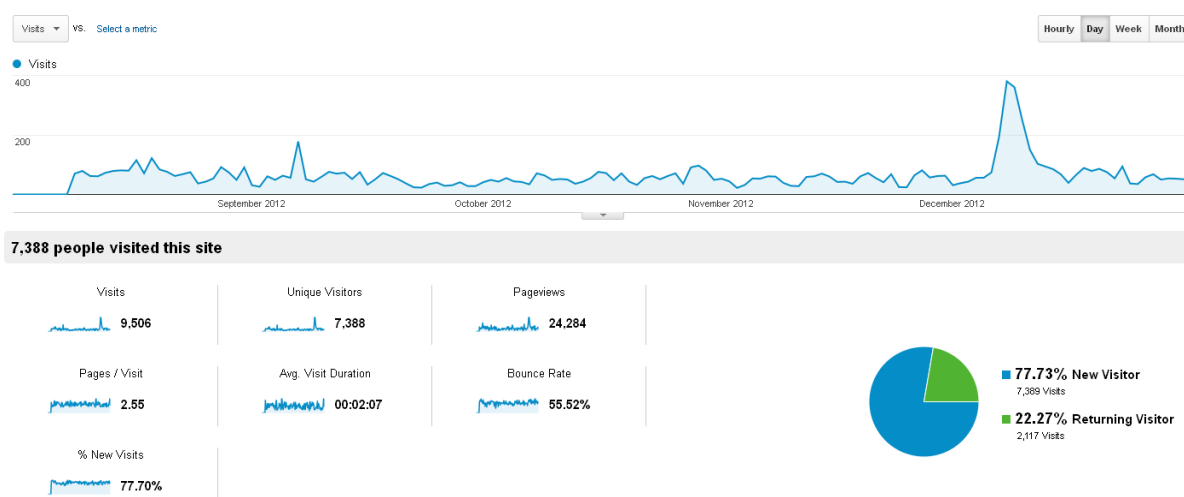
Although the *Twins* Newsletter is first and foremost a tool for communication with members, it also presents an opportunity to assess the accuracy of member address data. Using the

Newsletter and other communication methods, during 2012, the Registry received 867 Return to Sender (RTS) envelopes and 3271 replied paid envelopes, a difference of 581 RTS and 2969 reply paid envelopes less than the previous year. This response is vitally important to the ATR, alerting us to members who have moved. Upon receiving the RTS, the ATR initiates the tracing of relocated members through a range of tools, such as the White Pages, as well as following up on the second or third contacts provided by the ATR members. At the end of 2012, the Registry maintained current information on 93.4% of the members (only 6.6% of members' contact details required updating and are listed as "pending" in **Table 1**.

ATR Website

In the past years, the ATR has received a growing number of requests from researchers to use web surveys. The ATR is also aware that increased use of smartphones allows more individuals to access their email more readily. The website was revamped in 2011 and provides up-to-date and current material for major stakeholders, the twin and research community. For those members who do not have the resources to use a website, we included the traditional mechanisms to update their details: by emailing the ATR at twins-atr@unimelb.edu.au or by calling the ATR's free line, 1 800 037 021.

To keep ATR members connected with the latest in twin research and issues the ATR launched [Facebook](#), [Twitter](#), and [E-News](#). The ATR introduced Facebook in August 2011 as a means of engaging members on a more informal and current platform. By the end of 2012 the ATR had 2300 Facebook followers. In 18 months the ATR has built a following to over 3000 'likes' with a reach of approximately 7500. In late April 2012 the ATR joined Twitter and had 225 followers at the end of the year. Facebook and Twitter keeps members up-to-date with the latest on twin health and research, and enable twins to connect with each other. This allows the ATR a more immediate means of disseminating and sharing information about the multiple community and calls for participants in research studies.



The ATR started utilising Google Analytics in August 2012 to guide how to best use resources for the most impact. There were 7,388 people who visited the ATR website from September to December 2012, with 77.73% being a new visitor and 22.27% returning to the website. The ATR aims to utilise the information from Google Analytics to further develop a new site which is tabbed logically and enables easy navigation for visitors.

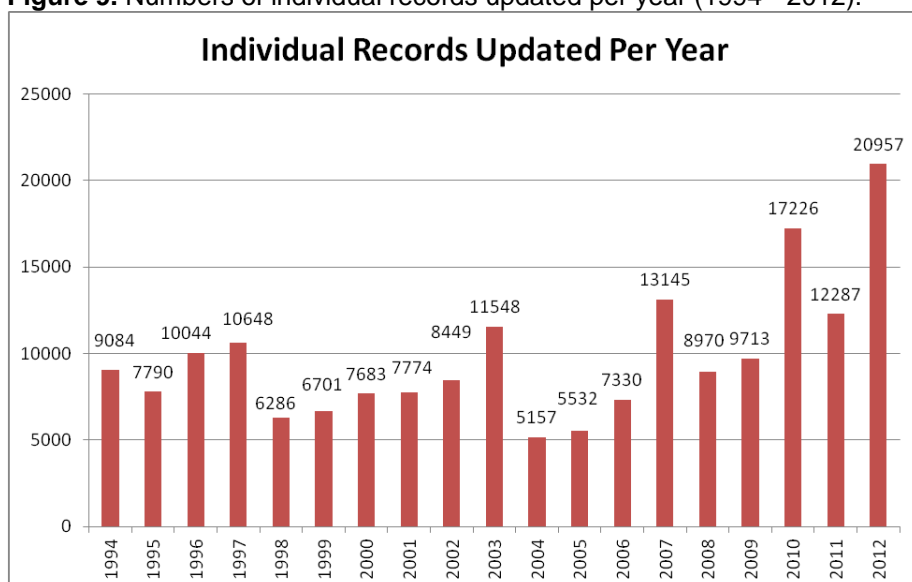
Record Updates

The ATR is aware that not all misdirected mail is Returned to Sender, and as such, the Registry also undertakes proactive tracing of its members. This is an ongoing and important

maintenance activity and ensures that the Registry remains viable. All prior addresses and any actions taken to trace members are recorded on the ATR database.

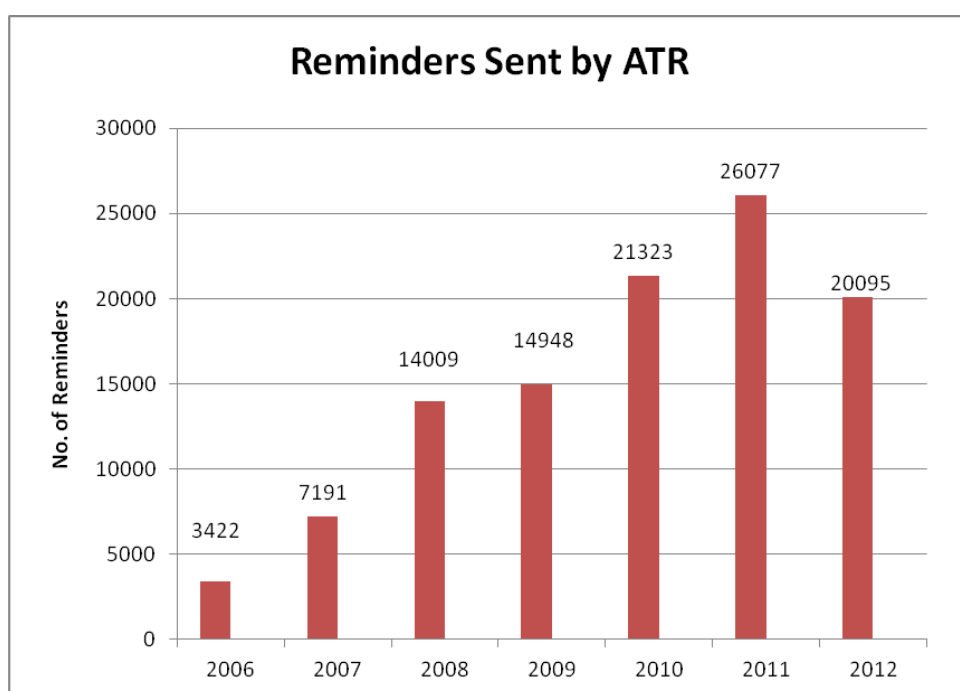
In 2012, a total of 20,957 individual twin and other contacts (i.e parent or secondary carer) member records were updated in the ATR database. This number includes an individual where their individual record, address information or phone number/email address has been edited, and those records followed-up due to receipt of an Return to Sender (RTS), and those generated through routine tracing or contact after a study approach has been sent. A count of all individual records updated yearly since 1994 is shown in **Figure 9**.

Figure 9. Numbers of individual records updated per year (1994 - 2012).



Telephone follow-up for studies remains a major tool for reaching high numbers of updated records. **Figure 10** illustrates the number of reminders and follow-ups being generated by ATR staff in the past seven years. There has been a decline in reminders in 2012 partly due to less study invitations being sent as in previous years.

Figure 10. Numbers of reminders sent by the ATR staff (2006 – 2012).



More than half (52%) of all reminders are undertaken by telephone (**Figure 11**), which although is a labour-intensive and costly exercise, is of great benefit as it provides a personal touch with

the ATR members and also increases response to studies facilitated by the ATR. The remaining reminders are through mail (9%) and e-mail (39%).

Figure 11. Number of reminders by category (phone, mail and email) since 2006.

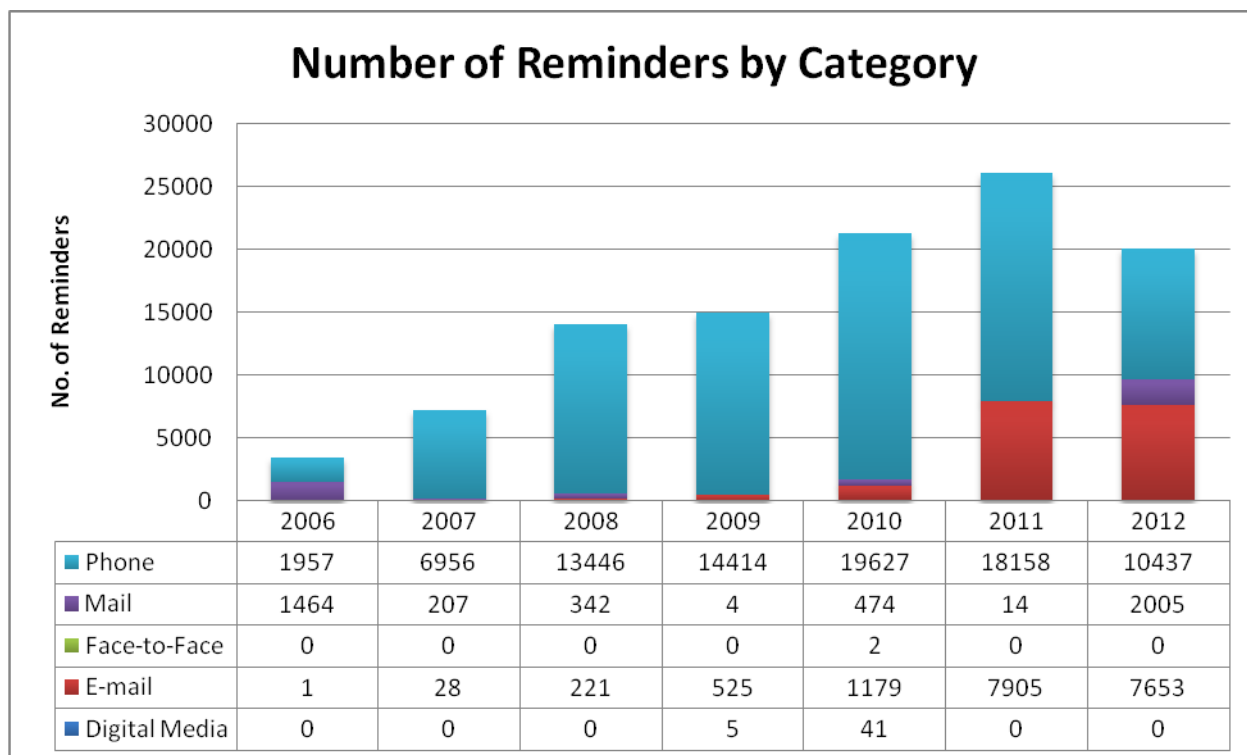


Figure 11 highlights the steady increase in email use as a tool to send reminders to ATR members, a declining number of phone reminders and an increase in the mail reminders. Although email is potentially far more efficient and economical, it also has a reduced response and tends to select for members who respond more favourably to emails. Thus, ATR is working to use both communication methods and to increase recorded email addresses, so that researchers and the ATR have this option of both communication tools.

Media Activities

Research and Media

In 2012 the ATR aimed to raise awareness and increase support in the general community for the role twins play in research. An example of this is the twin study run by Professor Leanne Williams at Westmead Hospital, Sydney, which detected a brain tumour in one of the twin participants in a routine EEG scan. This was a rare opportunity where research gave back to a participant and it resulted in a lifesaving diagnosis.

ATR members and identical twins brothers, Craig and Brenton Gurney, participated in a twin research study as a way of helping others, but it led to saving the life of one of them. Their story is the more extraordinary as it was Brenton who was concerned at first that he may have a brain tumour because of constant headaches. Brenton decided to join a twin research study which involved undertaking a brain MRI and he asked Craig to come along too as twin pairs were needed for the study.



Top Left: ATR members and identical twin brothers Craig and Brenton Gurney; Top Right: Brenton and Craig Gurney with ATR Advisory Board Chair, Vince Pollaers; Bottom Left: Representatives from the ATR, Westmead Private Hospital and the Brain Dynamics Centre. Bottom Right: Ear, Nose and Throat Specialist Dr. Narinder Singh, of Westmead Private Hospital, demonstrates some of the surgical procedures used in Craig's operation.

The results showed the all-clear for Brenton but, shockingly, led to the discovery of a tumour at the base of Craig's skull. Craig underwent a complex ten-and-a-half hour operation at Sydney's Westmead Private Hospital to remove a nearly five centimetre tumour, followed by 40 sessions of high-precision, 3D radiation treatment.

Craig is now back at work as a retail manager and is enjoying life with his family. Craig and Brenton urge twins to become involved in the registry and twin studies.

As twins, we have something special that we can use to help others. You could potentially save a life – and it may be your own – by becoming involved in research.

This story was covered by many in-print modes around Australia on 21 May 2012. Please follow the links to read more about the [Gurney Twins](#) or to view the [ATR media release](#).

2012 Twins Plus Festival

The 2012 Twins Plus Festival held in Melbourne in March was Australia's biggest ever festival for twins, which brought together a record 3000 twins, families and friends as well as higher number multiples, for one big celebration.

It was a day to celebrate all-things-twins and they came in all shapes and sizes and ages from newborn babies to the oldest set of twins aged 83. Highlights included appearances by celebrity fraternal twins, Isabella and Sofia Bliss, from Channel 10's *Junior Masterchef* and identical twins, Laura and Emily Sayers, from Channel 9's *The Block*.



Photo Collage from the Twins Plus Festival 2012 where over 3,000 twins and higher order multiples and their friends and families and twin researchers – enjoying a day of fun and festivity, music, clowns, lots of displays and researchers on hand to talk about their studies

As you would expect at a twins festival, there were many unique sights: identical twin policemen on patrol; identical twin clown unicyclists entertaining the crowds; twin singers, dancers and musicians performing in the *Multiples Got Talent Show*.

It seems twins love to be photographed and a big drawcard of the day was the all-in group photo plus the awards for the most alike and least alike twins. Visitors also enjoyed the speciality twin shopping, twin photo studio, displays from twin support groups, and the great rides and shows for all ages.

As a co-organiser of the event, the Australian Twin Registry attended in force with displays and twin researchers on hand to talk about their studies, and zygosity testing for twins who were unsure if they were identical or not. Thanks to our festival partner, the Australian Multiple Birth Association, and the following festival gold sponsors - AMBA, Toshiba and Think Twins.

In Press – articles in Newspapers, Magazines, TV, Radio and other media including online

In 2012 the ATR focused on increasing exposure in the media through the promotion of particular research projects. During the 12 months there were 49 in press articles in newspapers, magazines, TV, radio and other media including online. The majority of this coverage relates to the Twins+ Festival and the Gurney Research study (see above). Refer to [Appendix 2](#) – In Press Articles for all of the ATR media coverage during 2012.

Capacity Building - match, WATCH and WATR

WATCH/WATR Report

WATCH (Western Australian Twin Child Health) is Australia's first population-based twins and family cohort. It consists of 5,459 families who had one or more multiple births in Western Australia between 1980 and 1997 inclusive, identified from the Maternal and Child Health Research database in Perth. Records are linked to routine data sources, providing data on maternal and perinatal factors, some post-natal complications, deaths and all hospital admissions during childhood.

WATR (Western Australian Twin Registry) extends WATCH to include a population-based sampling of adults born between 1974 and 1979, and children born from 1998 onwards. During 2012 the ATR has continued the process of merging with the WATR to enable us to improve our services to the twin and research community. This will continue in 2013.

As of 2012, WATR plan to transfer all their twin contact details to the ATR so they may be accessed by approved researchers on a national level. This will be completed by 2013.

Match report

The Mothers and Twin Children (**match**) project recruits and collects data from mothers pregnant with twins. This cohort will be a resource for future research addressing the role of factors around the time of conception and during gestation as determinants of maternal and foetal health and development.

Activities in 2012 have been put on hold due to funding restrictions and will be reviewed. However, the ATR continues to provide a free Twins Pregnancy Booklet to all expecting parents through advertising on the ATR website and flyers in hospitals and maternal health centres.

SCIENTIFIC MERIT

Collaboration with researchers applying to the ATR to ensure that projects are of significant scientific merit and are appropriately described to ensure the ability of potential participants to provide informed consent

Current Research Studies

Building on a previous average (in 1999-2003) of 10 - 15 studies per year, the ATR aims to increase the number of studies supported per year to 15 - 20. This includes studies that:

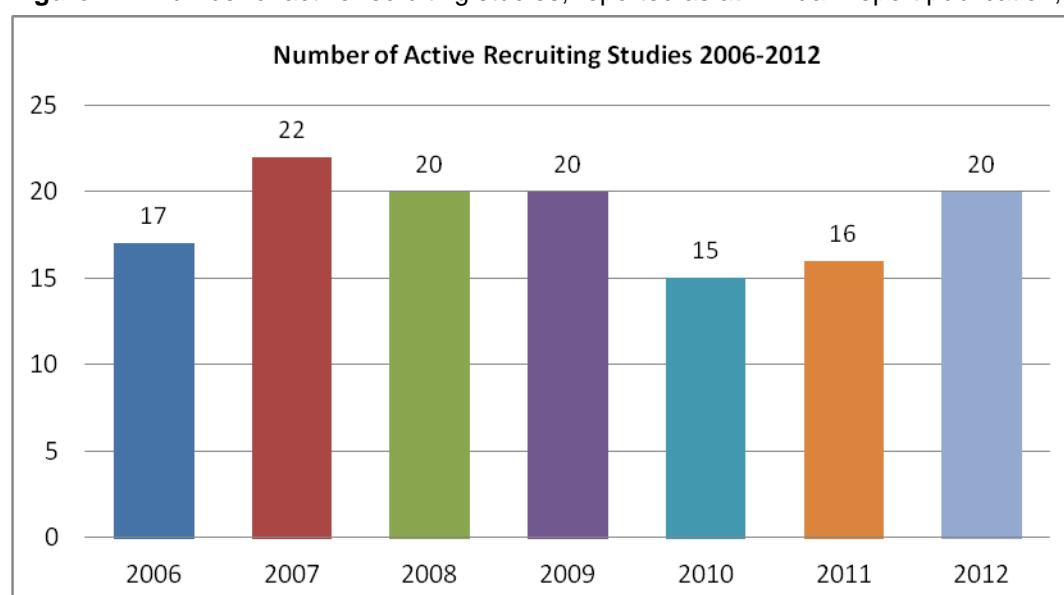
- are in the initial stages of planning and development;
- are involved in active recruitment;
- have completed or paused recruitment, but may require additional support for follow-up and clarification with members.

The total number of active and ongoing studies utilising ATR services and/or involving ATR members increased to 75 studies in 2012. This includes the active processing of 6 Expressions of Interests (EOIs) for new research, 7 new research applications (all as a result of approved EOIs) were processed throughout the year. In total, there were 20 active recruiting studies with participants in 2012, 4 of which were completely new, and the provision of ad hoc support to a further 55 studies in varying stages of study development, data collection, data analysis, and writing up. A complete count of all studies, by status, as of 31 December 2012, is shown in **Table 2** and a count of active recruiting studies in the past seven years is shown in **Figure 12**.

Table 2: Studies by Status 2012.

Study Status	Number
Application (EOIs, Full Application, Protocol Change)	16
Recruiting	20
Data Collection	6
Data Analysis	45
Writing Up/Publishing	4
TOTAL	91
<i>Completed</i>	<i>91</i>
GRAND TOTAL	182

Figure 12. Number of active recruiting studies, reported as at Annual Report publication, 2006 - 2012.



Researcher Reports

The Researcher Annual Progress Reports provided by the researchers and associated staff summarise the current activities undertaken by each study active in the current reporting period (1 January to 31 December 2012), major achievements for this period, and future plans.

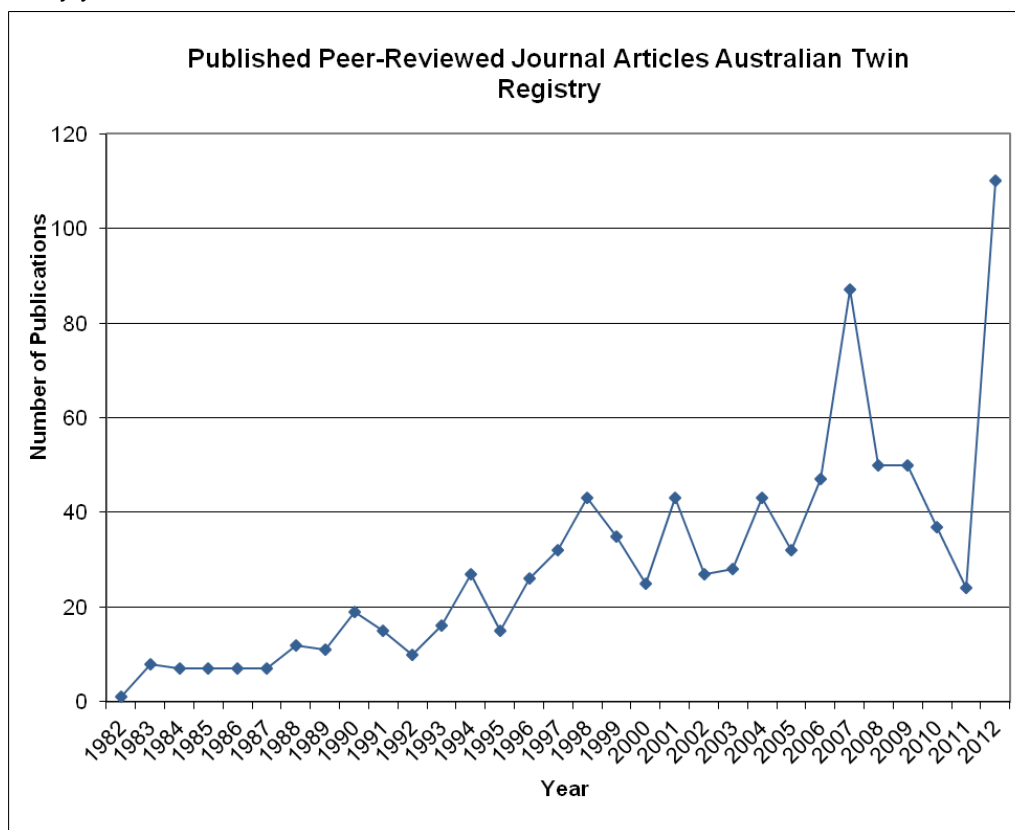
The Annual Researcher Satisfaction Survey has been fully integrated with the ATR's Annual Progress Report. Refer to Value Add section.

Publications

An important measure of the output of the ATR is the number of publications arising from studies supported by the facility. An important goal set by the ATR in the Enabling Grant was to increase the number of peer-reviewed articles to 50 per year.

In 2012, the ATR has recorded 110 peer-reviewed journal articles (**Figure 13**), 1 book, 3 book chapters, and 22 conference proceedings, for a total of 136 publications. The goal of having 50 peer-reviewed articles yearly was reached, several additional publications were reported to be in press or in preparation from 2011, were published and recorded in 2012. The list of all 2012 publications can be found in [Appendix 3](#).

Figure 13. Number of articles arising from ATR studies that were published in peer-reviewed journals every year since 1981.



Meetings and Conferences

- *Asia-Pacific Symposium on Genome Epidemiology Cohorts, South Korea, March 23-25th 2012.*

The ATR Director introduced the Australian Twin Registry to the Asia-Pacific Symposium on Genome Epidemiology Cohorts in South Korea.

- *The Joint 2nd World Congress on Twin Pregnancy: A Global Perspective and the 14th Congress of the International Society Twin Studies (ISTS): "The biology, genetics, clinical challenges and uniqueness of twin gestations", in Florence, Italy; April 1st – 4th 2012.*

The ATR Director and Manager attended the 4 day meeting and it is an opportunity to hear the latest, cutting-edge research on many biological and psychological features of twinship. The meeting emphasized the novel ways twins can enhance research across a wide range of disciplines. The conference consisted of both invited oral presentations as well as posters. The Director presented two research studies: '*Genes and Environment in cervical cancer: a classic twin study*' on April 2nd and twin research in genetic epidemiology entitled '*Missing Heritability: did it ever exist?*' on April 3rd.

The abstracts were included in Twin Research and Human Genetics Vol 15, No 2:201-202.

- *The 20th Victorian Convention of the Australian Multiple Birth Association (AMBA), Ivanhoe, Melbourne, 28th October 2012.*

The ATR Manager presented the ATR and how AMBA and the ATR could further work together to support the work of researchers, taking examples from past studies, and highlighting some of the current and upcoming research. Participation of ATR in the AMBA National Convention in 2011 strengthened the close relationship between the Registry and AMBA and also increased awareness of the ATR brand amongst the twin community.

In 2012 the ATR continued the ATR Club Support Initiative in financial support. The grants go towards supporting administration costs for promoting the ATR at club level, resulting in the transfer of contact details of parent with twins. In 2012 a total of 28 AMBA clubs around Australia applied for the grants. All clubs are asked to include a section in their membership forms which permits AMBA to pass on their contact details to receive more information about the ATR. In 2012 the ATR received 194 new registrations from this initiative.

- *The ATR Director was involved with a scoping session at the Charles Perkins Centre in Sydney, 13th December 2012 to investigate opportunities for future collaboration.*

The ATR Director continued to liaise on a monthly basis with the working group that is establishing the International Network of Twin Registries (INTR) to encourage the engagement of the registries in active collaborative research. The 2nd meeting of the INTR will meet in Seoul, South Korea in May 2013.

2012 Twins Plus Festival

The ATR co-hosted the 2012 Twins Plus Festival with the Australian Multiple Birth Association (AMBA) on 18th March 2012 at Caulfield Racecourse, 10am – 6pm. Refer to **Media Activities** section for more details.

Nearly 3000 twins, triplets and their families and friends came along to celebrate the special bond that twins and multiples share and the unique contribution they can make to research. Approximately 122 new registrations with the ATR were made on the day.

There were 10 researchers/stalls at the Festival conducting study or presenting their research study to the twin plus community which generated much interest. In particular, 250 twins and their families indicated their willingness to participate in research studies. One researcher commented '*It was great to meet other researchers at the 2012 Twin Festival, but more importantly, with twins who have already participated, or may be interested in, our future research*'.

Research Travel Grant Scheme

The Travel Grant Scheme supported a total of 17 early-career researchers (10 in Round 9 and 7 in Round 10) to attend relevant national and international research workshops and conferences relating to twin research.

Round 9 of the ATR Research Travel Grant Scheme was awarded in April 2012. Congratulations to the following successful recipients:

- Amir Batouli - Brain and Ageing Research Program, School of Psychiatry, Faculty of Medicine, University of New South Wales
- Gabiëlla Blokland - Genetic Epidemiology, Queensland Institute of Medical Research
- Jeffrey Craig – Early Life Epigenetics, Murdoch Childrens Research Institute, The Royal Childrens Hospital
- Justine Gatt – Discipline of Psychiatry and Westmead Millennium Institute
- Teresa Lee – Older Australian Twin Study, Brain and Ageing Research Program, University of New South Wales
- Yi Lu – Statistical Genetics, Queensland Institute of Medical Research
- Natalie Mills – Genetic Epidemiology, Queensland Institute of Medical Research
- Monica Rankin – Membership Director, ICOMBO, Member of INTR and AMBA
- Richard Saffery – Group Leader and Senior Research Fellow, Cancer, Disease and Developmental Epigenetics, Murdoch Childrens Research Institute, Royal Childrens Hospital
- Sally Staton – School of Psychology and Counselling, Queensland University of Technology

Round 10 of the ATR Research Travel Grant Scheme was awarded in September 2012. Congratulations to the following successful recipients:

- Jeffrey Craig - Early Life Epigenetics, Murdoch Childrens Research Institute, The Royal Childrens Hospital
- Jane Ebejer - Genetic Epidemiology, Queensland Institute of Medical Research
- Paulo Ferreira - Discipline of Physiotherapy, Faculty of Health Sciences, University of Sydney
- Lauren Gilbert – Department of Medicine, Royal Melbourne Hospital
- Yvonne Ho – Quantitative Genetics, Queensland Institute of Medical Research
- Negar Shahmoradi – Department of Endocrinology, Heidelberg Repatriation Hospital
- Xiaofang Wang – Department of Endocrinology and Medicine, Austin Health, the University of Melbourne

Grants provided opportunities for new researchers to attend diverse meetings and conferences. To date \$24,600 has been allocated to 44 young researchers since the beginning of this Enabling Grant.

PARTICIPATION

Judicious management and administration of approach to eligible twin members to inform them of a new research project, determine their interest in participation, and seek their permission to release their contact details to the researcher

Study Approaches

Mailouts to prospective participants for individual studies are a core component of the Registry's daily operations. Scheduling of mailouts and the total number of approaches sent is dependent on the requirements of the researcher. During 2012, **79** mailouts were conducted, with a total of **16,591** letters or emails were sent (**Table 3**).

Table 3: Total Number of mailouts and total letters by study in 2012.

Study ID	Study Title	No. Mailouts	Total No. Letters /Emails	RTS Rec'd	RP Mail Rec'd
2012-004	Twins Zygosity Assumptions	1	152	0	0
2012-004-1	Twins Zygosity Assumptions: online questionnaire	1	151	0	0
2010-003-1	OCD Study; Approach to Twins With 'Unknown' Zygosity	1	30	0	0
2011-002-1	Fat taste sensitivity in mono & dizygotic twin pairs	1	79	0	1
2012-001	Bone health in children and young people with epilepsy treated with anti epileptic drugs (AEDs)	2	400	0	3
2012-005	How Does Host Cell Influences HIV Diversification	3	302	9	56
2012-008	Genetic Determinants of Electrocardiographic Parameters	3	406	16	46
2010-005	Twin Musculoskeletal Health Study	3	84	1	77
2010-006	Beauty and the Eye of the Beholder	5	3874	3	0
2010-002	Are People Born to Live on the Edge or in the Mainstream?	6	2008	0	0
2012-003	A Twin Study of the NAPLAN	6	2729	64	712
2010-003	Obsessive-compulsive spectrum disorders: A population based twin study of major symptom dimensions	10	1990	89	132
2005-003-2	OATS Extra Component	1	90	0	59
2006-004	Genetic and environmental factors in invasive cervical cancer: a twin study	17	1592	65	714
2007-005-3	Growing Pains and Functional Pain Disorders	1	2	0	5
2007-005-4	Back Pain and Other Regional Pain Disorders in Australian Twin Families	1	435	6	296
2007-005-6	Common Pain Disorders of Childhood	2	238	2	173
2007-005-5	An investigation into the nature of Growing Pains in Australia: Abdominal Pain Ext	4	1003	28	414
2008-001-3	Effect of Menopause on the Structure of Bone	1	378	0	1
2008-001-2	Effect of Menopause on the Structure of Bone Reapproach	1	116	2	65
2008-004-1	The Emotional Well-being project phase 2	8	394	1	9
2009-003-2	Prevalence and risk factors of Lower Back Pain	1	138	0	4
2007-004	Artrial Fibrillation	0	0	0	2
2007-005-2	An investigation into the nature of Growing Pains in Australia	0	0	0	2
2008-004	Emotional Well-Being Project Ph1	0	0	0	6
2008-006	Genetics of Syncope and Breath Holding	0	0	0	2
2009-004	"Gut Number Sense"	0	0	7	7
2011-004	The heritability of the T cell activation expression signature in whole blood	0	0	0	1
Total		79	16591	293	2787

Table 3 shows these numbers by study and summarizes approaches for both Junior members (1 approach per family) and Senior members (1 approach per twin). The number quoted for each study also includes reminder mailouts. The last 6 studies in Table 3 have low RTS and Reply Paid mail received returns as they relate to responses from recruited members mailed out in 2011.

Telephone Follow Up

As part of its services, the ATR offers researchers the option of telephone follow-up, which can be used in conjunction with reminder letters or as a stand-alone, follow-up mechanism. This form of follow-up was used by most of the ATR actively recruiting studies during the reported period.

Telephone follow-up for studies is a significant component of the day-to-day work of Registry staff. The number of hours and resulting phone calls for study phone follow-up are outlined in **Table 4**. Please note, these figures do not include telephone calls and hours spent tracing twins who have changed address.

Table 4: Number of Calls and hours spent on the calls by the ATR staff in 2012

Study ID	Study Name	No. Phone Calls	Total Hrs
2010-002	Are People Born to Live on the Edge or in the Mainstream?	301	19
2010-003	Obsessive-compulsive spectrum disorders: A population based twin study of major symptom dimensions	3455	237.75
2010-003-1	OCD Study; Approach to Twins With 'Unknown' Zygosity	16	
2010-005	Twin Musculoskeletal Health Study	90	6.5
2010-006	Beauty and the Eye of the Beholder	6	
2011-003	Genetic and Environmental Contributions to Information Behaviour and Web Searching		4.25
2012-001	Bone health in children and young people with epilepsy treated with anti epileptic drugs (AEDs)	4	2.5
2012-003	A Twin Study of the NAPLAN	786	64.7
2012-004	Twins Zygosity Assumptions	25	
2012-004-1	Twins Zygosity Assumptions: online questionnaire	50	
2012-005	How Does Host Cell Influences HIV Diversification	396	22
2012-008	Genetic Determinants of Electrocardiographic Parameters	579	49
2005-003-2	OATS Extra Component	74	5.75
2006-004	Genetic and environmental factors in invasive cervical cancer: a twin study	2185	200.5
2007-005-3	Growing Pains and Functional Pain Disorders	2	
2007-005-4	Back Pain and Other Regional Pain Disorders in Australian Twin Families	536	36
2007-005-5	Common Pain Disorders of Childhood	1158	109.25
2007-005-6	An investigation into the nature of Growing Pains in Australia: Abdominal Pain Ext	316	29
2008-001-2	Effect of Menopause on the Structure of Bone	85	6.75
2008-004-1	The Emotional Well-being project phase 2	373	30.25
Total		10,437	823.2

A slight decline in researchers requesting Telephone Follow Up and the Registry's adoption of a Verbal Response protocol, where a twin gives agreement over the telephone regarding their willingness to participate in a study, has reduced the number of follow up mailouts and approaches required. (Refer to **Figure 11** to see the changing response modes to studies). In 2012 there were a large number of mailouts compared to the previous year (14), and as costs and overheads have risen, researchers have requested an increase in email follow up, resulting in a decrease in Telephone Follow Up from 18,158 in 2011 to 10,437 in 2012.

Responses to Invitations to Participate in Research Studies

The overall response for a study is defined as the number of 'Positive ("Yes")' and 'Negative ("No")' responses over the total number of twin members approached. The 'Response Rate' (RR) is an important statistical element in the interpretation of research results and as such, the ATR aims to obtain a response from as many members approached as possible.

Figure 14 shows double response rates, or double "yes", for most active studies in 2012, and for those studies that have been ongoing since 2010 in three categories – Broad Selection Study Approach – Survey Based, Restrictive Study Selection Criteria, and Follow-Up for Additional Participation.

Figure 14: Study response statistics to date for most active studies 2010-2012 (ongoing and recruiting)

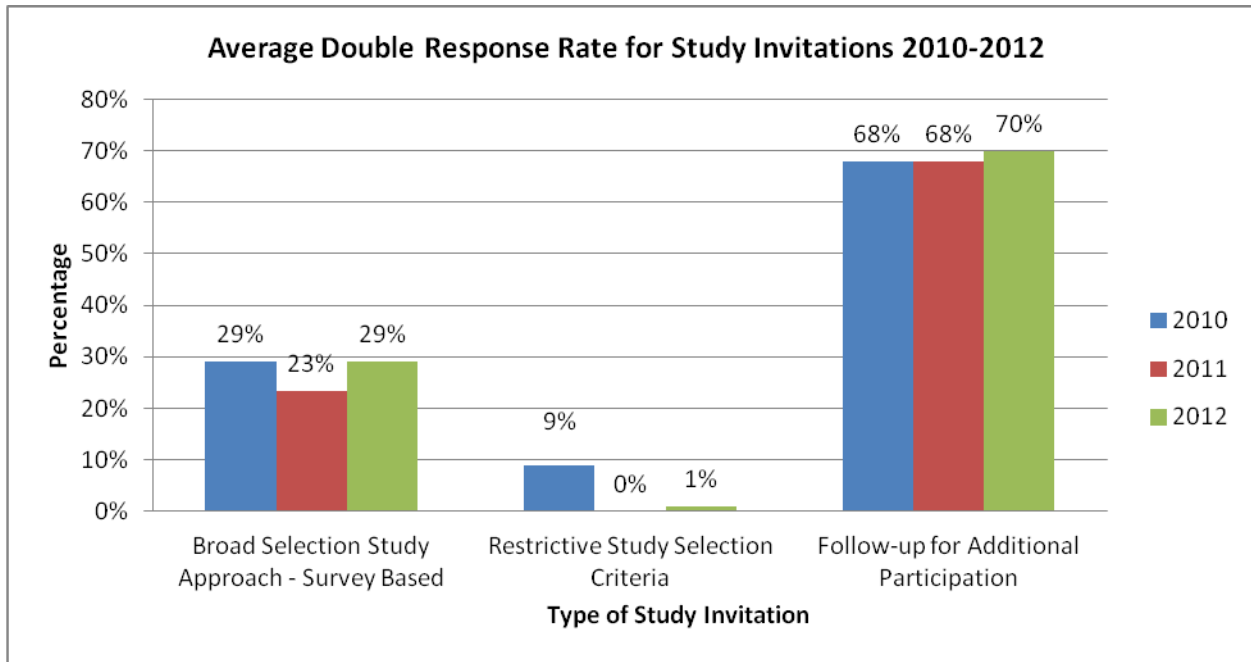
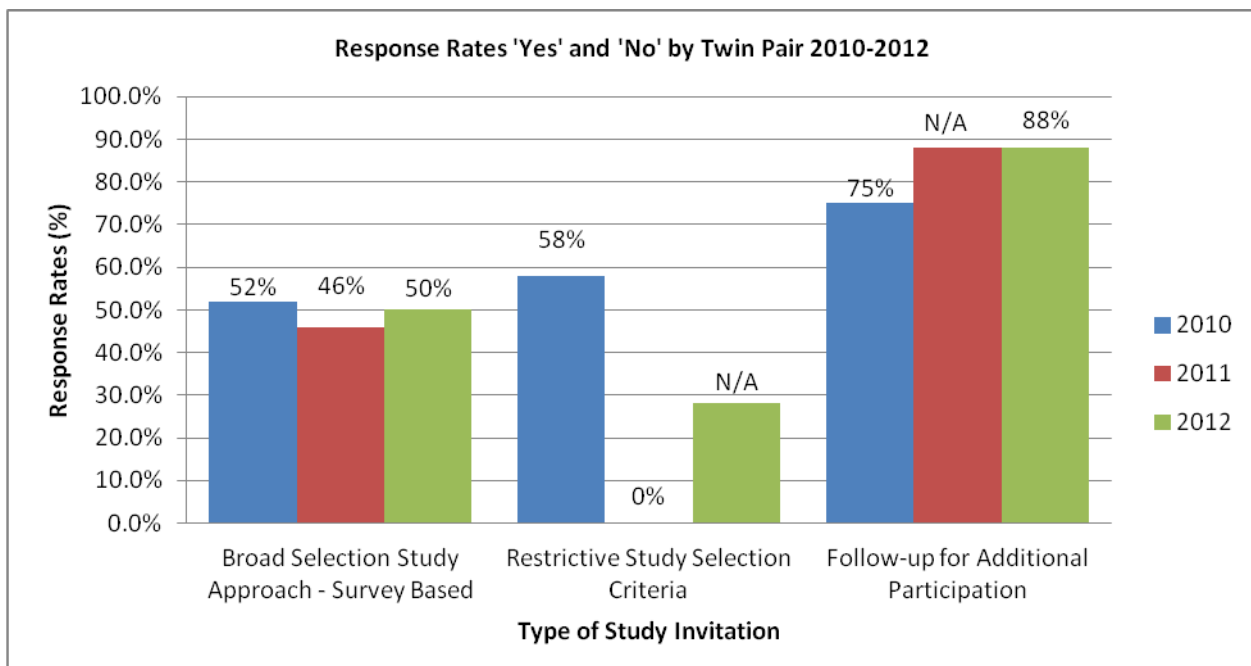


Figure 15 shows study response rates with a hard 'yes' and a hard 'no' for 2010-2012 years. The positive strong 'yes'/'no' response shows that the engagement of the ATR membership.

Figure 15: Study response statistics to date for most active studies 2010-2012 (ongoing and recruiting)



Response rates to Registry mailouts will depend on the study showing different study levels and responses. For example, standard open studies which have few criteria on participants often receive more positive study responses, such as the emotional well-being and lower back pain studies, whereas a study requiring a specific criteria or re-approach to participants is often due to 'hard to get' participants, such as the anti-epileptic and bone health study.

Response rates to Registry mailouts appear to be higher for those studies approaching either families with young twins (under 18 years old) or older, adult twins (40 years and older). Twins between the ages of 18 and 40 years have the highest 'NR (*Nil Response obtained*)' and 'Negative' RR and are the most difficult group for which to maintain current contact information. 'Negative' RR also include twins who are ineligible to participate in a study based on the criteria set by researchers, for example, where the member does not display a particular trait or does/does not suffer from a particular disease.

Adverse Effects and Complaints

The ATR takes any complaint from members seriously and endeavours to promptly resolve the issue presented. The ATR requires all adverse effects and complaints to be communicated to ATR Management.

During the reporting period, one ATR member filed a complaint to the Registry about a study facilitated by ATR. ATR ensured the resolution of this complaint was addressed by the study researchers in a timely manner.

VALUE-ADD

Development of projects and programs to value-add to twin research in Australia

Quality Improvement Project

In response to the NHMRC's requirement for stakeholder feedback, the ATR implemented a Quality Assurance (QA) Program in 2006 that incorporates stakeholder satisfaction feedback, monitors the quality of service delivery to twin members and researchers, and identifies critical points during the implementation and roll out of a research project where reflection and forward planning are important to maintain quality. The ATR has two major stakeholders: twin members and researchers working with the ATR.

The 2012, the Annual Researcher Satisfaction survey was administered as part of the Annual Progress Report submitted by researchers. It requested feedback relating to the previous 12 months on:

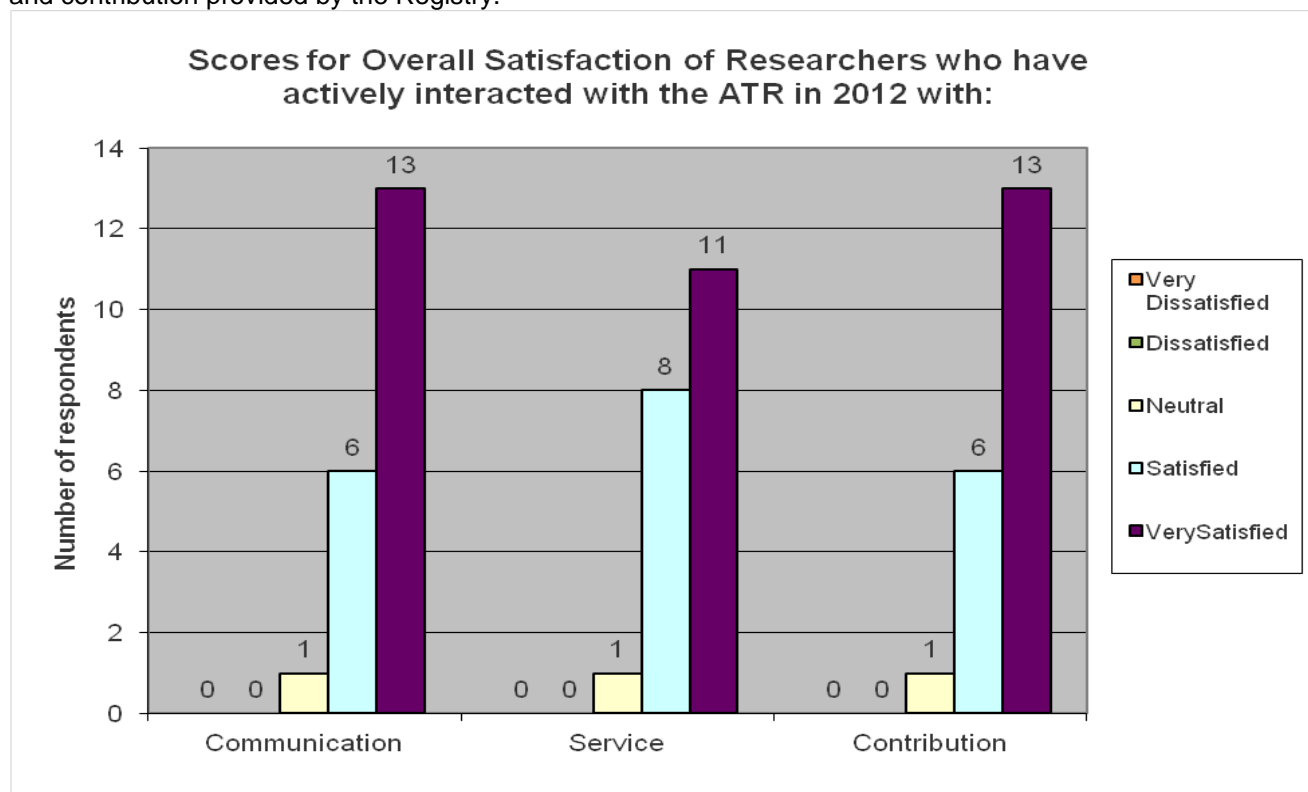
- (1) overall satisfaction with the researchers' communication with the ATR;
- (2) overall satisfaction with the services that the ATR provided; and
- (3) the value of the contribution that the ATR made to the overall research project

Responses were recorded as

1 - Very Dissatisfied / 2 - Dissatisfied / 3 - Neutral / 4 - Satisfied / 5 - Very Satisfied

We received feedback from 20 research groups. Overall, researchers were very satisfied with the communication and service provided by the ATR and the contribution the ATR has made to their project (**Figure 16**).

Figure 16. Overall satisfaction scores from researchers, evaluating communication with ATR, and service and contribution provided by the Registry.



ATR Data Index Project

To accomplish the ATR's goal of fostering new collaborations for researchers, the Registry created a web-based, searchable index of questions and topics covered by all previous studies conducted via the ATR. The index was launched in 2009 and it is accessible at

http://www.twins.org.au/study_index/BasicSearch.php.

On this webpage, users can conduct searches based on keywords and specific criteria. A search generates a list of all previous studies matching the search items, including ATR study ID number, study title, Investigator/s, host institution/s, year/s study conducted, and study status (completed, in progress, etc). Advanced searches return the types of twins approached for each study (e.g. MZ/DZ; male/female; adult/junior combinations); any questionnaires or tests administered; and any other measures or samples taken. Records can be systematically reviewed and checked against existing hard copy files to ensure listings are complete.

Researchers interested in utilising these existing data contact the Registry initially, who then fosters a link with the originating research group.

The Ark

In 2010, the ATR became a collaborative development partner for The Ark, an international project based at the University of Western Australia. The Ark suite of informatics tools will be used by the ATR in the day-to-day operation and will also be made available to researchers conducting twin research. Access to the ATR hosted instance of The Ark software will minimise the need for researchers to develop and host software to manage their studies. The open source licensing of The Ark means that researchers are also free to install separate local instances to support single studies or whole institutions, depending on their needs. Software modules to support recruitment, subject management, electronic questionnaires, and manage phenotypic and biospecimen data are currently in place.

During 2012 there was significant development of The Ark, an open source software information management system for the medical research community. A new data extraction module was completed, allowing researchers to filter and export data across demographic, phenotypic and biospecimen modules. The Ark now also includes a work tracking module that is capable of accurately tracking the status, time invested, and billing for researcher's requests. This module is flexible and extensible, meaning that it can handle many types of work requests and billable items such as mailouts and telephone correspondence. Pedigree modelling functionality is also under development and due for completion in the latter part of 2013. A key aspect of the pedigree module is its capability of modelling twin relationships; monozygotic and di-zygotic relationships can be captured in a flexible and user-friendly manner, and dynamic pedigree diagrams can be created at the click of a button. Together, these new modules will be used to manage existing ATR datasets, in addition to data captured by the forthcoming online Health and Lifestyle questionnaire.

GOVERNANCE

Governance of the ATR in a fair, transparent and equitable manner

ATR Management

As of 31 December 2012, the ATR Management comprised:

- Prof John Hopper, AM, Director, Australian Twin Registry; NHMRC Senior Principal Research Fellow; Director (Research), Centre for MEGA Epidemiology, University of Melbourne
- Dr Debra Foley, Deputy Director (Research), Australian Twin Registry; ORYGEN Research Centre
- Mr Paul White, Deputy Director (Informatics), University of Western Australia
- Mr Vincent Pollaers, Chair, Advisory Board
- Kate Murphy, ATR Manager
- Nilmini Jayasuriya, ATR Assistant Manager
- Jenny Boadle, ATR Study Coordinator
- Shaie O'Brien, ATR Project Support Officer

Any member of ATR Management with a potential conflict of interest is required to declare this interest prior to any relevant discussions. Persons with a conflict of interest in any study are excluded from review or application approval processes of that study.

Members of the Advisory Committee are available to help act as independent reviewers. In the event that the Director or Deputy Director is involved in a study as a researcher, they take no part in the approval process. If both are involved or unavailable, an independent person is brought in to oversee the processing of the application.

Advisory Board and Charter

In 2012, the Advisory Board members were:

- Mr Vincent Pollaers (Chair, Twin Representative, New South Wales)
- Mrs Ann Marie Harli (AMBA Representative, Victoria)
- Dr Keith Horsley (Australian Institute of Health and Welfare, Retired)
- Dr Paul Jelfs (Australian Bureau of Statistics, Australian Capital Territory)
- A/Professor Paul Lancaster (University of Sydney, Retired)
- Mr William Mackerras (Twin Representative, Australian Capital Territory)
- Prof Margaret Otlowksi (University of Tasmania, Tasmania)
- Prof David Ravine (Western Australian Institute of Medical Research, Western Australia)
- A/Prof David Whiteman (Queensland Institute of Medical Research, Queensland)

Ex-officio:

- Prof John Hopper (Director, ATR, University of Melbourne)
- Dr Debra Foley (Deputy Director, ATR, ORYGEN Research Centre)
- Mr Paul White, Deputy Director (Informatics), University of Western Australia

ATR Staff

The ATR is administered by The University of Melbourne and is situated in the Centre for MEGA Epidemiology, School of Population Health. In 2012, the ATR continues to employ an ATR Manager, ATR Study Coordinator, ATR Assistant Manager, a Marketing Officer, Project Support Officer, Project Assistant and an Administration Assistant, five casual staff (equivalent of 2.0 EFT), and a part time Database Manager.

The ATR provided an honorarium to the Director and both part-time Deputy Directors.

Dispute Resolution Process

The Dispute Resolution Process approved by the Advisory Board enables impartial and transparent management of any dispute arising between the ATR and stakeholders. No action was necessary under this process in 2012.

ATR Budget

The ATR welcomes donations towards the administration and management of the Registry. Donors are provided with a receipt. Donations may be earmarked for specific activity.

We are very grateful for all the support we receive from Registry members and the wider community who have donated in 2012 towards a total of \$55.

The names of the ATR donors are listed below:

Vivien Irene Kennedy

The NHMRC Enabling Grant Special Facilities Scheme provides the ATR with \$500,000 per annum between 2010 and 2014. The ATR also recovers costs associated with approaching twins for studies from researchers.

Appendix 2 – In Press Articles 2012

Newspaper

- (2012). Double Dose of Fun on Twins Day. [Stonnington Leader](#).
- (2012). Multiplying the Fun. [Port Phillip Leader](#).
- (2012). The power of two. [Voice \(Melbourne University\)](#).
- Balfour, C. (2012). Sibling Rivalry at Fest. [Whittlesea Leader](#).
- Beale, A. (2012). Double Trouble. [LaTrobe Valley Express](#).
- Bruce, M. (2012). Fascinating World of Twins. [The Sunday Mail QLD](#).
- Byrne, B. (2012). Blackburn sees double easy. [Whitehorse Leader](#).
- Critchley, C. (2012). Twice as Nice. [The Weekly Review](#).
- Horin, A. (2012). Headaches led to discovery of tumour - in other twin. [Brisbane Times](#).
- Horin, A. (2012). Headaches led to discovery of tumour - in other twin. [Sydney Morning Herald](#).
- Horin, A. (2012). Headaches led to discovery of tumour - in other twin. [The Border Watch](#).
- Horin, A. (2012). Headaches led to discovery of tumour - in other twin. [WA Today](#).
- Hudson, F. (2012). No you're not seeing double, you're seeing twins. [Daily Mercury](#). Mackay, QLD.
- Lee, J. (2012). You could be forgiven for seeing double at this festival gathering. [The Age](#).
- Maiden, S. (2012). Twins in a spin for festival. [Sunday Herald Sun](#).
- Pearlman, J. (2012). Identical twins headaches lead to life-saving discovery of tumour. [The Telegraph \(UK\)](#).
- Pincock, S. (2012). Same Same But Different. [Australian Doctor Magazine](#).
- Pincock, S. (2012). Two of a kind but not quite the same. [Australian](#).
- Power, L. (2012). The reasons Santa makes a list and checks it twice. [The Daily Telegraph](#).
- Scott, R. (2012). Twin Study Helps Explain Fainting. [The Voice](#), University of Melbourne.
- Signy, H. (2012). Twin Power. [Readers Digest](#).
- Tuohy, W. (2012). Secret Life of Twins (spread). [Herald Sun Weekend](#).

Magazine

- (2012). Do You Believe in Twin-Tuition? [That's Life Magazine](#).
- (2012). My Brother's Sixth Sense Saved My Life. [New Idea](#).
- (2012). My Twin Sensed My Cancer. [Who Magazine](#).
- Walker, L. (2012). Cancer tests the close bond of identical twin brothers. [AMBA Magazine](#).

Radio / Television

- (2012). Double Trouble at the Twins Festival. [Ch9 5pm News \(Live Cross\)](#).
- (2012). Double Trouble at the Twins Festival. [Ch9 News 6pm \(full story\)](#).
- (2012). Festival [ABC1 7pm news \(end credit vision\)](#).
- (2012). Seeing Double: Double Trouble. [Ch 9 Today Program](#).
- (2012). Twin convinces brother to join life-saving study. [ABC News 7pm](#).
- (2012). Twins and their unique bond. [ABC Sydney 702 Afternoons](#).
- (2012). Twins Festival Hits Melbourne. [ABC 774 Radio](#).
- (2012). Twins 'Sixth Sense' locates tumour. [Ch 9 5pm news Sydney](#).
- (2012). Twin-tuition. [Today Show](#).
- Burns, L. (2012). Festival Promotion. [ABC Evening Radio](#).
- Hodge, E. (2012). Gurney twins and their unique bond. [The Bunch Breakfast Radio Show](#). Perth.
- Hughes, D. (2012). Gurney twins and their unique bond. [Hughsey and Kate Breakfast Show](#), Nova FM. Melbourne.
- Huntington, S. (2012). Double the Value; How Researching Twins Benefits Everyone. [Up Close Podcast \(Melbourne University\)](#).
- Lehmo, B. A. (2012). Festival Promotion. [Radio Gold FM morning talkback](#).

- Salter, E. (2012). Twin-tuition. Ch 9 Today Show.
- Sandilands, K. (2012). Gurney twins and medical research. Kyle and Jackie O Breakfast Show.
- Walter, D. (2012). Festival Promotion. 3AW Afternoon Drive program.
- Whittemore, M. (2012). Twins and Research (Interview with ATR Chairman). Radio 2GB. Sydney.
- Wilson, M. (2012). Gurney twins and medical research. Radio Live Drive. Auckland, New Zealand.

Online

- (2012). Brenton Gurney, Saves Twin Brother, Craig Gurney, From Life-Threatening Brain Tumour with Sixth Sense. Huffington Post online.
- (2012). Seeing Double: Why twins are so important for health and medical research. The Conversation.
- (2012). Sixth sense saves man's life after harmless headaches suffered by identical twin. Daily Mail online.
- Bellamy, M. (2012). Twins 'Sixth Sense' locates tumour. nine msn.

Appendix 3: Publications List 2012

Peer-reviewed publications

Agrawal, A., E. C. Nelson, et al. (2012). "Cannabinoid receptor genotype moderation of the effects of childhood physical abuse on anhedonia and depression." Arch Gen Psychiatry **69**(7): 732-740.

Agrawal, A., K. J. Verweij, et al. (2012). "The genetics of addiction-a translational perspective." Transl Psychiatry **2**: e140.

Amin, N., E. Byrne, et al. (2012). "Genome-wide association analysis of coffee drinking suggests association with CYP1A1/CYP1A2 and NRCAM." Mol Psychiatry **17**(11): 1116-1129.

Amin, N., J. J. Hottenga, et al. (2012). "Refining genome-wide linkage intervals using a meta-analysis of genome-wide association studies identifies loci influencing personality dimensions." Eur J Hum Genet.

Arnett AB, P. B., Willcutt E, Dmitrieva J, Byrne B, Samuelsson S, Olson RK. (2012). "A Cross-Lagged Model of the Development of ADHD Inattention Symptoms and Rapid Naming Speed." J Abnorm Child Psychol.

Asselbergs, F. W., Y. Guo, et al. (2012). "Large-scale gene-centric meta-analysis across 32 studies identifies multiple lipid loci." Am J Hum Genet **91**(5): 823-838.

Batouli, S. A., P. S. Sachdev, et al. (2012). "The heritability of brain metabolites on proton magnetic resonance spectroscopy in older individuals." Neuroimage **62**(1): 281-289.

Baughman, H. M., E. A. Giammarco, et al. (2012). "A behavioral genetic study of humor styles in an Australian sample." Twin Res Hum Genet **15**(5): 663-667.

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