

Annual Report

1 January - 31 December 2011



Level 3/207 Bouverie Street
Carlton, Victoria 3010

Telephone: 1 800 037 021 (*free call Australia wide*)

www.twins.org.au

TABLE OF CONTENTS

- EXECUTIVE SUMMARY3**
- ATR OVERVIEW6**
 - About the Australian Twin Registry6*
 - Potential for Twin Research6*
 - Funding6*
 - Values7*
- THE REGISTRY8**
 - Database8*
 - Membership8*
 - Recruitment9*
 - Currency and Accuracy of Membership Data11*
 - ATR Website12*
 - Record Updates12*
 - Media Activities15*
 - Capacity Building - match, WATCH and WATR16*
- SCIENTIFIC MERIT17**
 - Current Research Studies17*
 - Researcher Reports18*
 - Publications18*
 - Meetings and Conferences18*
 - Research Travel Grant Scheme19*
- PARTICIPATION20**
 - Study Approaches20*
 - Telephone Follow Up21*
 - Responses to Invitations to Participate in Research Studies22*
 - Adverse Effects and Complaints22*
- VALUE-ADD23**
 - Quality Improvement Project23*
 - ATR Data Index Project23*
- GOVERNANCE25**
 - ATR Management25*
 - Advisory Board and Charter25*
 - ATR Staff26*
 - Dispute Resolution Process26*
 - ATR Budget26*
- Appendix 1: Researcher Reports**
- Appendix 2: Publications List (2011)**

EXECUTIVE SUMMARY

Welcome to the 2011 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 2011 reporting period coincides with the second 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 2011 the ATR made significant progress towards attaining this vision. Following below is a summary of the 2011 highlights and achievements:

Highlights and Achievements for 2011

- ATR Membership numbers grew, in line with the goal set in the Enabling Grant, as 1,415 new sets of twins and triplets were registered in 2011, and 1,347 became active members of the Registry. A large number of new members were registered through the research collaboration between ATR and the Western Australian Twin Registry (WATR). The introduction of online registration has also enabled twins to more readily join the ATR.
- For the third consecutive year the number of research studies actively supported by the ATR increased to a record 82. This resulted in 30,418 approaches to participants and which involved 1,295 hours of telephone follow-up.
- The research benefits enabled by the ATR were significant, with 24 peer-reviewed articles based on ATR-related studies published, as well as 2 book chapters and 6 abstracts and posters.
- The ATR increased its focus on the ATR brand in 2011, refreshing their logo and paying particular attention to its online strategy. The ATR website, <http://twins.org.au/>, received a “new look and feel” and the ATR established its presence on Facebook. The revised logo has been integrated into all the ATR's communications materials.
- The ATR sponsored (at Silver Level) and participated in the 2011 39th National Convention of The Australian Multiple Birth Association (AMBA), which was held in Sydney between 21st and 23rd of October 2011. This popular event attracts many delegates from the multiple birth community across Australia who participate in interactive workshops that enable club sharing across clubs and states. At the convention, the ATR launched the ATR Club Initiative Support Grant, which was particularly successful. Participation of ATR in the AMBA National Convention strengthened the close relationship between the Registry and AMBA and also increased awareness of the ATR brand amongst the twin community.
- The ATR organized and hosted the ATR Twin Workshop *“Research Involving Twins: an invaluable component of a medical researcher's repertoire”*, held on February 28th at the Bio21 Institute in Melbourne.
- The first meeting of the International Network of Twin Registries (INTR) was organized by the ATR on March 1st at the University of Melbourne. This working group of several international registries discussed the structure of INTR and sharing of resources among member registries.
- The ATR moved offices from Swanston Street into the modern building of the Melbourne School of Population Health at 207 Bouverie Street, Level 3.



International leaders of twin registries and studies, Prof Jaakko Kaprio, Dr Jack Goldberg, Dr Jennifer Harris, Dr Isabel Fortier and Professor John Hopper who presented at the ATR Twin Workshop in February 2011

Overall, 2011 has been a year of great success for the ATR in research, funding and Registry growth. The outlook for 2012 promises further progress in all these areas of interest.

Outlook for 2012

- The ATR will review and enhance the range and quality of services that it currently provides to the research community, optimising the ATR's ability to support research that has the potential to contribute to the health and wellbeing of Australians.
 - This will be achieved by monitoring our services to current researchers with a researcher quality service program collecting feedback over 3 stages of the life span of the study;
 - Provide 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;
 - Develop a Health and Lifestyle Questionnaire for our members to complete so as to better target twins suitable for the researcher's areas of interest;
 - Provide 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;
 - Lead the initiative to be part of an International Network of Twin Registries; and
 - Re-design our quarterly community update to researchers.
- The ATR will develop and implement a marketing initiative aimed at engaging more effectively with current members as well as increasing the number of twins registered as members with the ATR, thus increasing the pool of members potentially available to participate in research studies.
 - Initially the focus will be on engaging our current members with frequent study approaches and communications. We plan to use multiple media approaches to achieve this via mailed newsletters, E - news, Facebook,

twitter, online satisfaction surveys and direct phone calls to collect feedback from specific study experiences.

- The ATR plans to increase its exposure to the wider community via national media releases on research articles, events such as the Twins Plus Festival for 2012 and to continue its collaboration with AMBA and other like-minded organisations.



- Raising the profile of the ATR Patrons and establishing a group of ATR Ambassadors that collectively represent all age groups, zygosities and backgrounds, which will enable the ATR to 'spread the word' more effectively.

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 2011, the ATR maintained information on 37,877 sets of twins and triplets, and supported 82 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.



Funding

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

Enabling Grants fund Special Facilities, including biospecimen and data repositories, computational facilities and disease/attribute registries. This highlights the fact that ATR is not a private resource generated by a group of researchers for use in a particular study or program, but is a resource available for the wider use of all Australian researchers including those who have not previously conducted twin studies.

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 does not undertake research itself but acts as facilitator of 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 Registry database launched in 2006 enables the ATR to more accurately be reimbursed by researchers for work done on their behalf for 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.

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 2011, the database held data on 76,030 individuals representing 37,601 twin pairs and 276 triplets (total number of 37,877 sets).

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 72.8% twin pairs have both members active, and an additional 6.5% of members' contact details require updating (recorded as Pending). Junior members represent approximately 30% of the entire registry, the remaining being senior members.

Table 1: Twin Pair Status Combination as of 31 December 2011. 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.

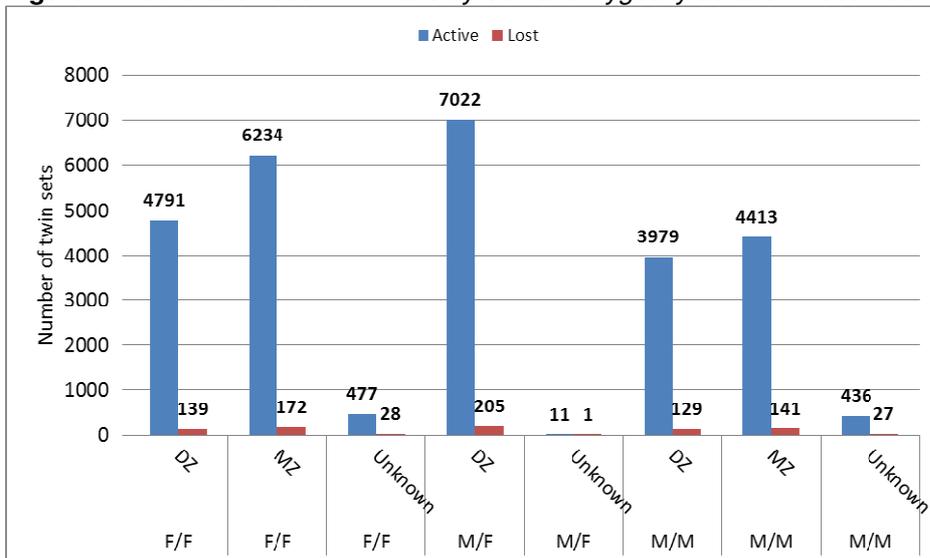
T1/T2 Status	Active	Deceased	Lost	Lost OS	In-active	Questionnaire	Newsletter	OS	Duplicate	Pending	Total
Active	27363										27363
Deceased	350	900									1250
Lost	66	5	911								982
Lost (O/S)	2	0	2	12							16
Inactive	408	225	13	0	2088						2734
Questionnaire	285	4	0	0	1	473					763
Newsletter	90	28	4	0	23	1	235				381
OS	147	1	0	0	5	3	0	227			383
Duplicate	0	1	0	0	0	0	0	0	262		263
Pending	853	32	24	0	58	18	18	10	0	2453	3466

37601

Currently, one third of the active ATR members are junior (0-19 years) and the rest of two thirds are adult.

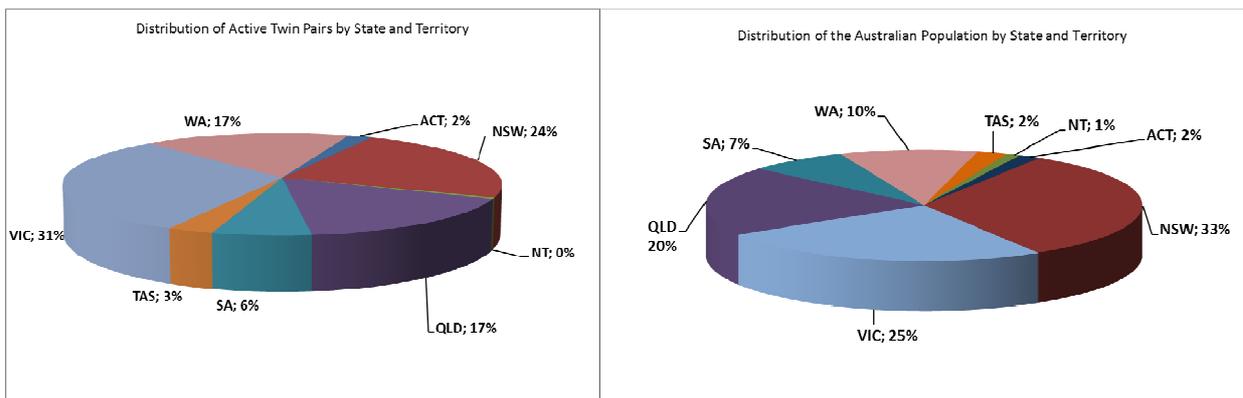
The current numbers of active and lost twin pairs by sex and zygosity are shown in **Figure 1**.

Figure 1. Active and Lost Twin Pairs by Sex and Zygosity as at 31 December 2011.



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 2010). 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 2011 (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 24,578 of the 27,363 shown as Active/Active in Table 1.*

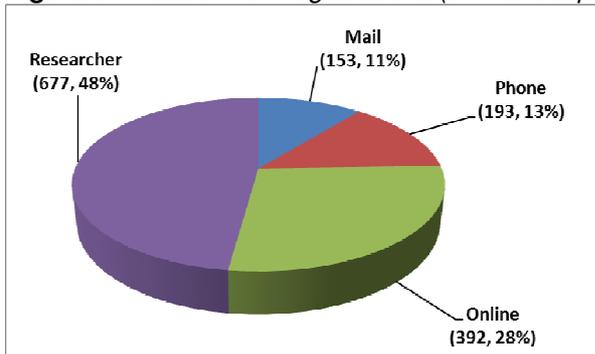


Recruitment

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.

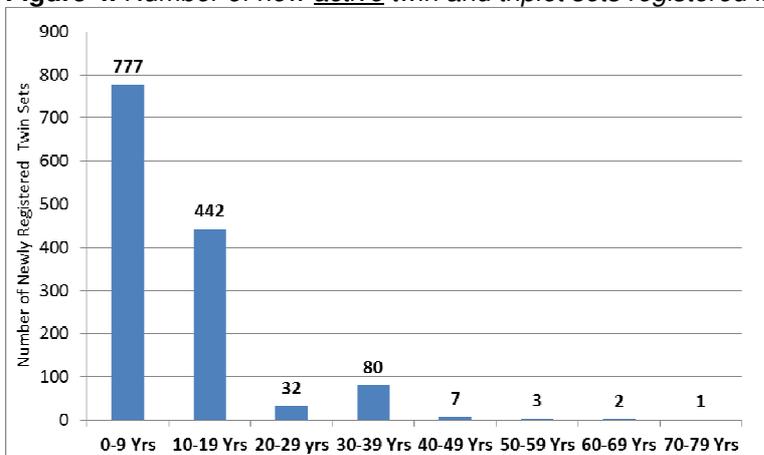
In the reporting period, 1 January to 31 December 2011, the ATR added membership details on 1,383 sets of twins and 32 sets of triplets, for a total of 1,415 sets. This recruitment of 2862 new members in 2011 puts the Registry on track to achieve its 5-year goal. The majority of new members (677 of the total 1,415 sets; 48%) were registered via researcher involvement (**Figure 3**) through WATR. We welcomed a large number of members, at the researchers' invitation, from Western Australia into the ATR.

Figure 3. Mode of new registrations (twin and triplet sets) in 2011.



The majority of new members (85%; or 496 sets of twins and 10 sets of triplets out of 583 total) enrolling with the ATR during the reporting period were aged 0-9 years, a feature that has remained relatively consistent over the last 20 years (**Figure 4**).

Figure 4. Number of new active twin and triplet sets registered in 2011 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 2011. Thus, most new members came from Western Australia (54%), followed by Victoria (18%) and New South Wales (13%) (**Figure 5**). The numbers of new registrations by year since 1987 are represented in **Figure 6**.

Figure 5. 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.*

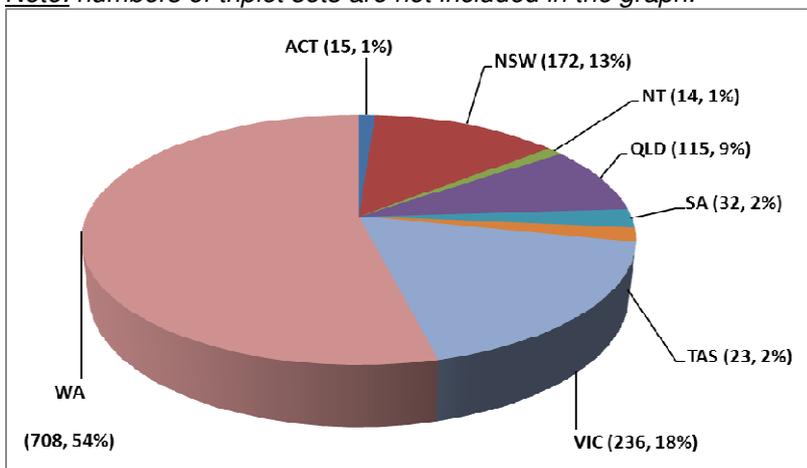
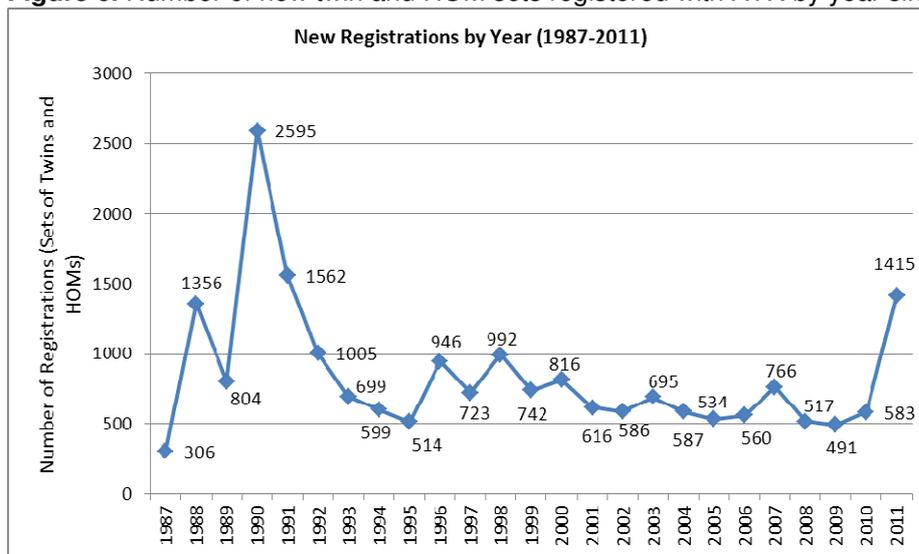
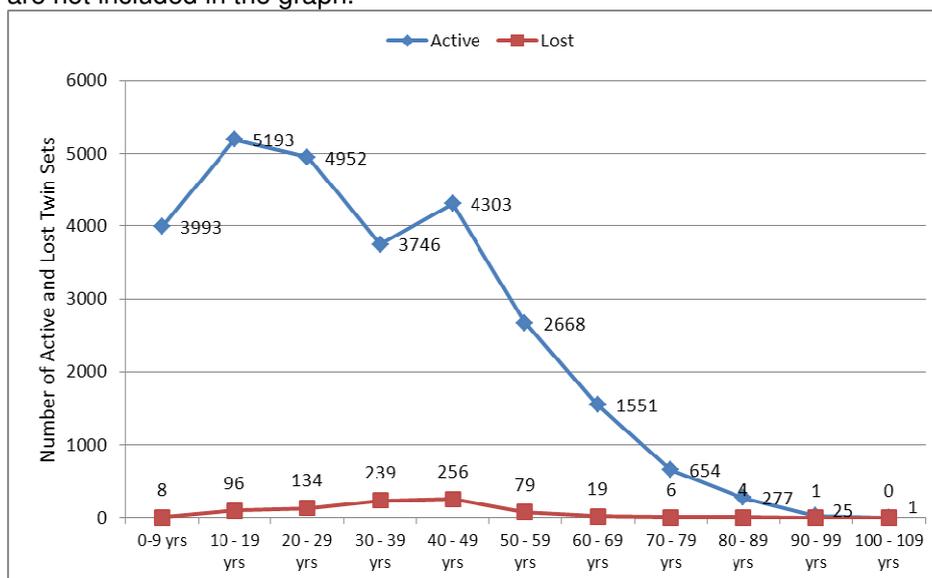


Figure 6. Number of new twin and HOM sets registered with ATR by year since 1987.



The distribution of active and lost pairs of twins, across the Registry, is shown relative to the age groups of members in **Figure 7**.

Figure 7. Active and lost twin pairs shown by age group, as at 31 December 2011. Note: data on triplets are not included in the graph.

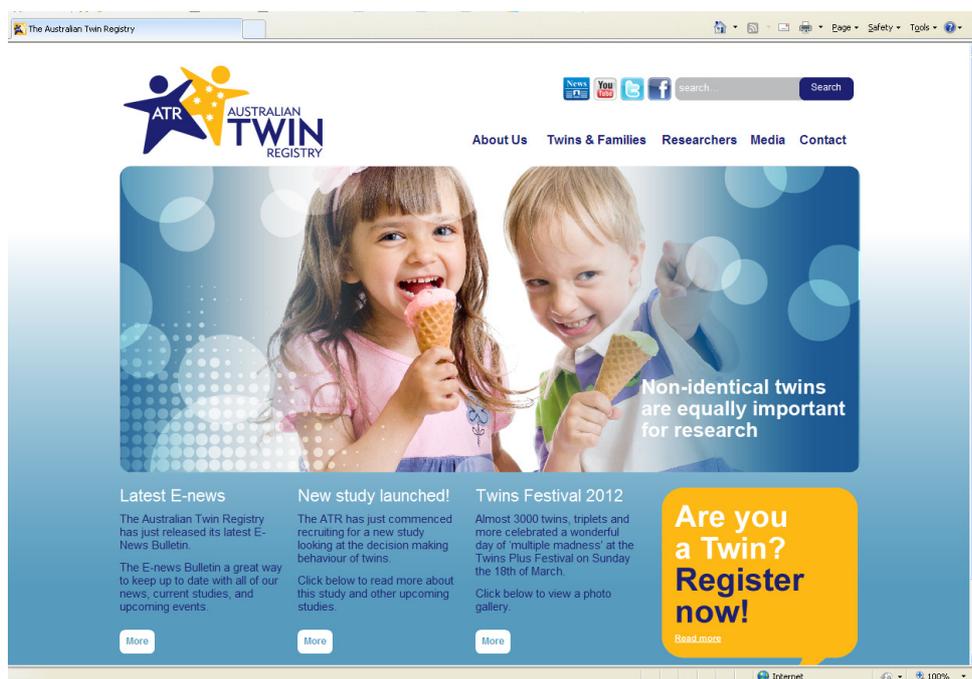


Currency and Accuracy of Membership Data

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 2011, the Registry received 874 Return to Sender (RTS) envelopes and 5756 replied paid envelopes. 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 2011, the Registry maintained current information on 93.5% of the members (only 6.5% 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. Thus, in 2010, the ATR initiated a focused process of collection of email contact from the members and used the 2010 *Twins* Newsletter, sent to 53,024 households, to capture these email addresses.

Continuing this initiative in 2011, the ATR tailored a new website that allows twins to register online and members to visit and deposit their updated details – this information could then flow directly to the database, limiting double handling of the data. It was also an opportunity to ask members to update zygosity status and to let the registry know their preferred way of receiving the *Twins* Newsletter (electronically or via post). 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.

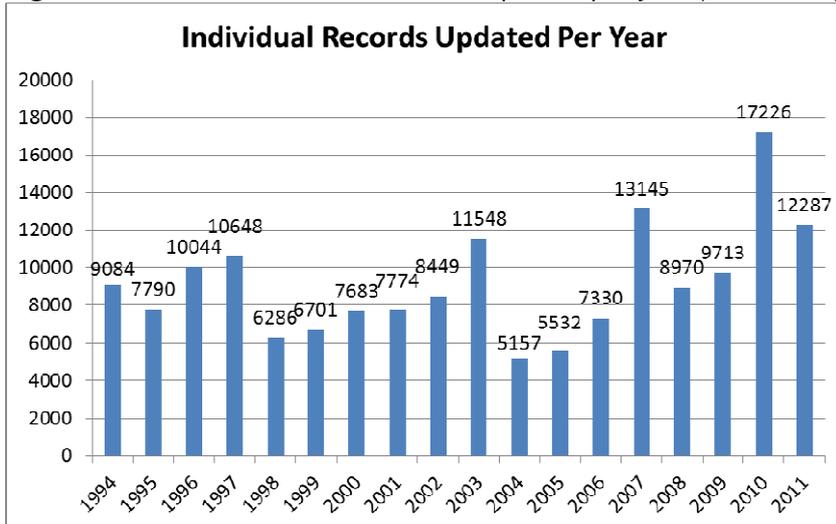
The new 'look and feel' of the website has made it more attractive and easier to navigate around. We have introduced a media tab to provide up to date media releases to our members and allow media to have access to frequently asked questions about twin research.

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.

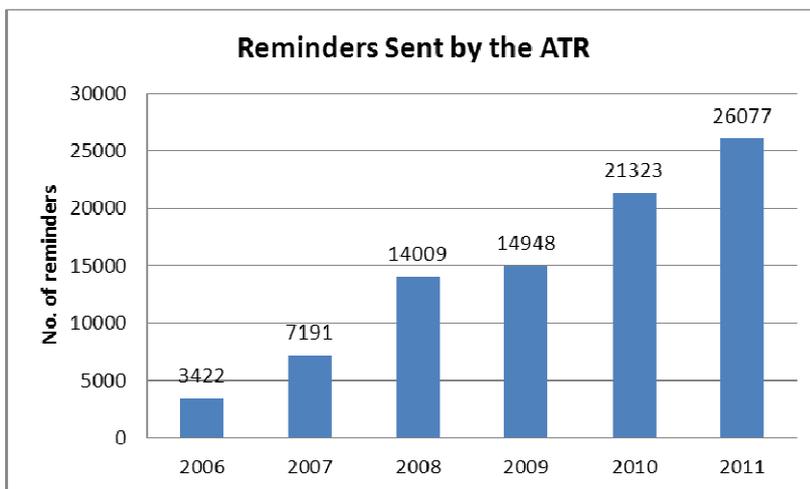
In 2011, a total of 12,287 member records were updated in the ATR database. This number includes those records followed-up due to receipt of an RTS, and those generated through routine tracing or contact after a study approach has been sent. A count of all individual records updated yearly since 1994 is shown in **Figure 8**.

Figure 8. Numbers of individual records updated per year (1994-2011).



Telephone follow-up for studies remains a major tool for reaching high numbers of updated records. **Figure 9** illustrates the number of reminders and follow-ups being generated by ATR staff in the past six years.

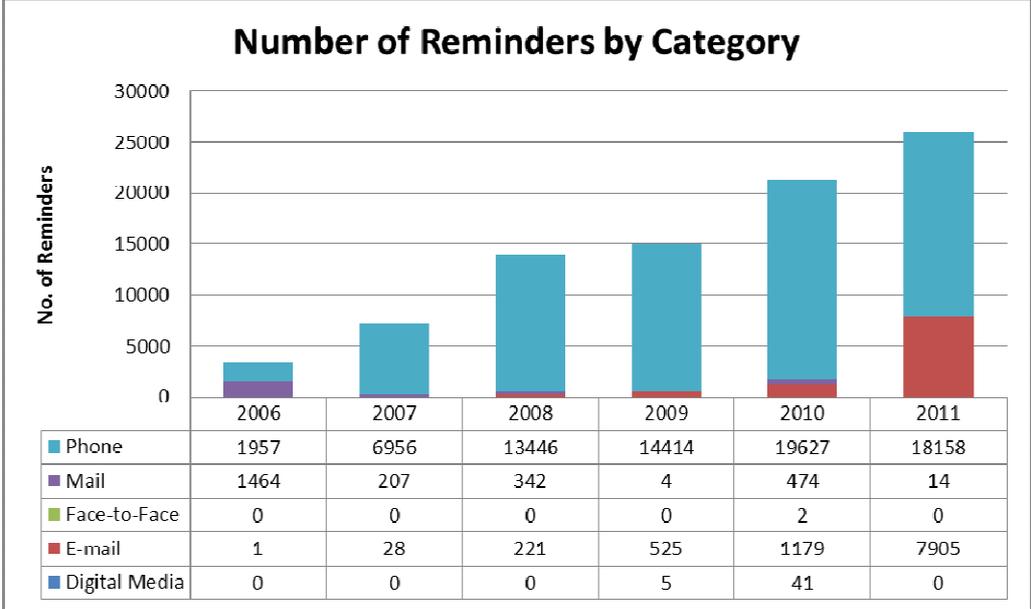
Figure 9. Numbers of reminders sent by the ATR staff (2006 – 2011).



More than 90% of all reminders are undertaken by telephone (**Fig. 10**), 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. 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.

Figure 10 highlights the increase in email use as a tool to send reminders to ATR members.

Figure 10. Number of reminders by category (phone, mail and email) since 2006.



Media Activities



In 2011, the ATR invited identical twin members who have expressed interest in media related work to respond to an invitation from Channel 10 that was for attendance of a celebratory twin BBQ with famous AFL identical twins. The BBQ took place on the 7th of May and celebrated identical twins Brad and Chris Scott who were coaching against each other; this is the first time in Australian sport that two identical twins had coached at the highest level.

Brad and Chris Scott at an AFL press conference



Celebrity twins Laura and Emily Sayers, 25, who participated in the TV show **The Block**, became the new ambassadors for the ATR in October 2011. This event was covered by Elissa Doherty in a Herald Sun article published on 13 October 2011

<http://www.heraldsun.com.au/entertainment/twins-with-a-taste-for-science/story-e6frf96f-1226165260032>).

They have already enrolled and participated in a research study that aims to understand why some people desire fatty foods more than others and whether there is a link between this desire and weight gain.

Celebrity twins Laura and Emily Sayers photographed during their study participation.

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. As a satellite project supported by the ATR, all twins and triplets enrolled in WATR are informed they are automatically registered with the ATR.

During 2011 WATR has continued to actively recruit twins born between 2005 and 2006 in Western Australia and transferred twin contact details to the ATR.

Going forward, WATR plan to transfer all their twin contact details to the ATR so they may be accessed by approved researchers on a national level.

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 2011 have been put on hold, while we are submitting applications for continuation of funding for this project.

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.

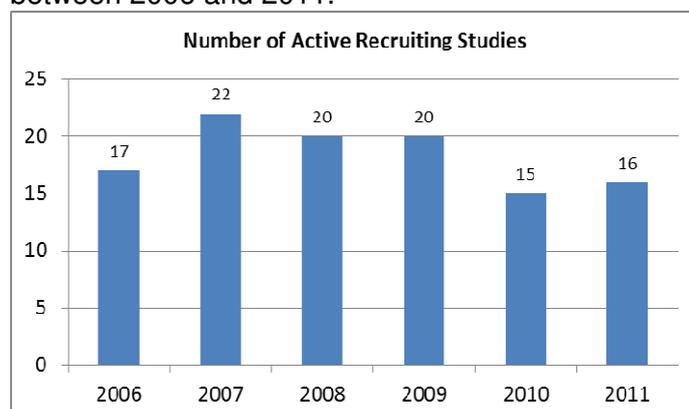
The total number of active and ongoing studies utilising ATR services and/or involving ATR members increased to 82 studies in 2011. This includes the active processing of 6 Expressions of Interests (EOIs) for new research, 5 new research applications (all as a result of approved EOIs), the active recruitment of participants to 16 studies, and the provision of ad hoc support to a further 57 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 2011, is shown in **Table 2** and a count of active recruiting studies in the past five years is shown in **Figure 11**.

Table 2: Studies by Status 2011.

Study Status	Number
Application (EOIs, Full Application, Protocol Change)	14
Recruiting and Data Collection	25
Data Analysis	27
Ongoing Programs	13
Writing Up/Publishing	3
TOTAL	82
<i>Completed</i>	
	90
<i>Abandoned (including abandoned EOIs due to unsuccessful funding)</i>	
	34
<i>On hold</i>	
	5

Figure 11. Number of active recruiting studies, reported as at Annual Report publication, between 2006 and 2011.



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 2011), 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 page 23.

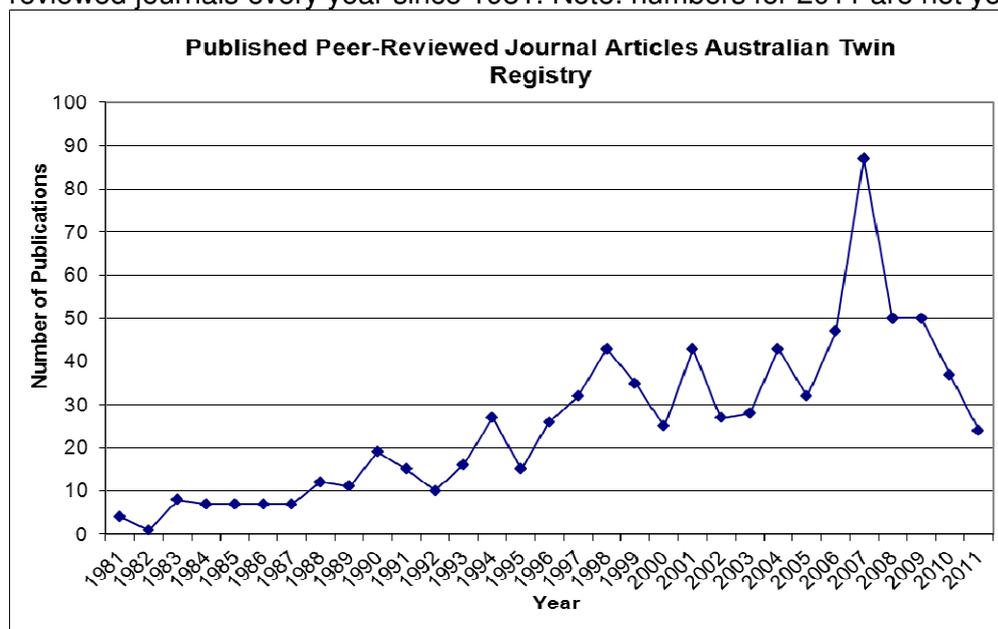
Publications

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 2011, the ATR has recorded 24 peer-reviewed articles (**Figure 12**), 2 book chapters, and 6 abstracts and posters, for a total of 32 publications. Although the goal of having 50 peer-reviewed articles yearly was not reached, several additional publications were reported to be in press or in preparation. In addition, many of the older studies have ended and newer studies are not expected to publish too soon after being started.

The list of all 2011 publications can be found in [Appendix 2](#).

Figure 12. Number of articles arising from ATR studies that were published in peer-reviewed journals every year since 1981. Note: numbers for 2011 are not yet complete.



Meetings and Conferences

- *“Research Involving Twins: an invaluable component of a medical researcher’s repertoire”, Bio21 Institute, Melbourne; February 28th 2011.*

The ATR organized and hosted this twin workshop, which brought together internationally renowned speakers from numerous twin registries around the world, including US, Europe and South Korea. This one-day meeting highlighted the involvement of twins in medical and health-related research. The meeting emphasized the novel ways twins can enhance research across a wide range of disciplines.

The event was aimed at researchers at all levels including early to mid-career scientists who previously have not included twin studies in their research portfolio. The conference consisted of both invited oral presentations as well as posters.

International speakers:

Dr Isabel Fortier

Director Research and Development, Public Population Project in Genomics, Montreal, Canada

Dr Jack Goldberg

Vietnam Era Twin Registry and University of Washington Twin Registry, Seattle, WA, USA

Dr Jennifer Harris

Division of Epidemiology, The Norwegian Institute of Public Health, Oslo, Norway

Prof Jaakko Kaprio

University of Helsinki and National Institute for Health and Welfare, Helsinki, Finland

Dr Joohon Sung

Seoul National University School of Public Health, The Healthy Twin Study and National Twin-Family Registry, Korea

- *The first meeting of the International Network of Twin Registries Epidemiological (INTREPID), University of Melbourne, Centre for MEGA Epidemiology, March 1st 2011.*

This working group was hosted by the ATR. Bringing several international registries together to discuss the structure of INTREPID and sharing of resources among member registries. This powerful concept of forming an International Twin Registry would allow collaborations on a global scale resulting in harmonisation of primary data on a scale never achieved before.

- *The 39th National Convention of The Australian Multiple Birth Association (AMBA), Sydney, Darling Harbour, 21st - 23rd October 2011.*

The ATR sponsored this event at Silver Level. This popular event attracts many delegates from the multiple birth community across Australia who participate in interactive workshops that enable club sharing across clubs and states. At the convention, the ATR opened the ATR club initiative support grant. Participation of ATR in the AMBA National Convention strengthened the close relationship between the Registry and AMBA and also increased awareness of the ATR brand amongst the twin community.

Research Travel Grant Scheme

Round 8 of the ATR Research Travel Grant Scheme was awarded in April 2011. Congratulations to the following successful recipients:

- Karin Verweij - Genetic Epidemiology, Queensland Institute of Medical Research
- Daniela Ribeiro - School of Dentistry, University of Adelaide
- Paul Sanfilippo - Centre for Eye Research Australia, Melbourne
- Miriam Mosing - Genetic Epidemiology, Queensland Institute of Medical Research
- Amir Batouli - School of Psychiatry, Faculty of Medicine, University of New South Wales
- Atika Ashar - School of Dentistry, University of Adelaide
- Gabriella Blokland - Genetic Epidemiology, Queensland Institute of Medical Research
- Paulo Ferreira - Discipline of Physiotherapy, Faculty of Health Sciences, University of Sydney
- Cindy Chapman - Pain Research Unit, Sydney Children's Hospital

Grants provided opportunities for new researchers to attend diverse meetings and conferences.

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 2011, **219** mailouts were conducted, with a total of **30,418** letters or emails were sent.

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.

Table 3: Number of mailouts and total letters by study in 2011.

Study ID	Study Title	No. Mailouts	Total No. Letters/emails	RTS Rcvd	RP Mail Rcvd
2005-003	The Twin Study of Brain Ageing and Cognition	2	118	2	67
2006-004	Genetic and Environmental Factors in Invasive Cervical Cancer: A Twin Study	31	2678	65	1727
2007-005-2	An investigation into the nature of Growing Pains in Australia	13	1601	44	726
2007-005-3	Growing Pains and Functional Pain Disorders	20	454	0	357
2008-001-1	Effect of Menopause on the Structure of Bone	1	372	-	-
2008-001-2	Effect of Menopause on the Structure of Bone	12	1068	19	381
2008-002-2	Genes, Diabetes Mellitus and Dementia; re-approach	2	58	0	35
2008-004	Pathways to affective disorders: interactions between genes, environment and biological mechanisms	37	3392	135	791
2008-004-1	The emotional well-being project phase 2	18	442	1	21
2009-003-1	Prevalence and Risk Factors of Lower Back Pain; Re-approach	1	129	-	-
2009-004	Gut Number Sense in Twins	29	7788	225	688
2010-003	Obsessive-compulsive spectrum disorders	21	4960	15	47
2010-004	How your brain recognises who you are	1	54	-	-
2010-005	Twin Musculoskeletal Health Study	1	302	2	274
2010-006	Beauty and the Eye of the Beholder	11	4500	121	0
2011-002	Fat taste sensitivity in monozygotic twin pairs	8	802	33	152
2011-003	Genetic and Environmental Contributions to Information Behaviour and Web Searching	7	1300	-	-
2011-004	The heritability of T cell activation expression signature in whole blood	4	400	8	97
TOTAL		219	30,418	670	5,363

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 increasingly popular 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.

A steady increase 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.

Table 4: Number of calls and hours spent on the calls by the ATR staff in 2011.

Study No.	Study Name	No. Phone Calls	Total Hrs	Total Hrs Chargeable
2010-001	Pilot study of adult socio-economic position and cardio-vascular risk in twins		2.75	2.3
2010-003	Obsessive-compulsive spectrum disorders: a population based twin study of major symptom dimensions	2094	141.5	108.5
2010-004	How Your Brain Recognises Who You Are - Finding the Neural Correlates of Autobiographical Visual Self Recognition	27	4	4
2010-005	Twin Musculoskeletal Health Study	166	10.5	10.1
2010-006	Beauty and the Eye of the Beholder	222	16.5	14.4
2011-002	Fat taste sensitivity in monozygotic twin pairs	1006	68.75	57.1
2011-003	Genetic and Environmental Contributions to Information Behaviour and Web Searching	20	2	2
2011-004	The heritability of the T cell activation expression signature in whole blood	560	35.25	31.9
2005-003	The Twin Study of Brain Ageing and Cognition	109	10	9.8
2006-004	Genetic and environmental factors in invasive cervical cancer: a twin study	4325	257.25	229.8
2007-005-2	An investigation into the nature of Growing Pains in Australia.	1671	113.75	102.3
2007-005-3	Growing Pains and Functional Pain Disorders	5	0.75	0.75
2008-001-2	Effect of Menopause on the Structure of Bone	1462	111.5	101.4
2008-002-2	Genes, Diabetes Mellitus and Dementia; re-approach	69	6.75	6.4
2008-004	Pathways to Affective Disorders: Interactions between Genes, Environment and Biological Mechanisms	5715	462.35	403.9
2008-004-1	The Emotional Well-being project phase 2	401	29.25	28.9
2008-006	Genetics of Syncope and Breath Holding	1	0.25	0.25
2009-003-1	Prevalence and Risk Factors of Lower Back Pain - Re-Approach to Existing Participants	1		
2009-004	Gut Number Sense in Twins	299	22	21
Total		18,153	1,295.1	1,134.8

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. **Table 5** shows response rates for most active studies.

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.

Table 5: Study response statistics to date for most active studies (ongoing and recruiting).

Study ID	Study Name	Total RR	Positive RR	Negative RR	NR RR	Total Pairs Approached	Total Responses
2008-002	Genes, Diabetes Mellitus and Dementia	96%	42%	51%	4%	177	170
2010-004	How Your Brain Recognises Who You Are - Finding the Neural Correlates of Autobiographical Visual Self Recognition	33%	12%	11%	67%	93	31
2005-002	Molecular Genetics of Inattention in Australia	77%	35%	39%	23%	1337	1030
2005-003	The Twin Study of Brain Ageing and Cognition	95%	45%	49%	5%	992	943
2005-003-1	The Twin Study of Brain Ageing and Cognition - Phase 2	100%	76%	24%	0%	212	212
2006-004	Genetic and environmental factors in invasive cervical cancer: a twin study	82%	41%	30%	18%	4607	3797
2007-004	Role of genetic and environmental factors in atrial fibrillation	78%	36%	40%	22%	936	726
2007-005-2	An investigation into the nature of Growing Pains in Australia.	37%	22%	15%	63%	2906	1070
2007-005-3	Growing Pains and Functional Pain Disorders	48%	48%	0%	52%	483	232
2007-006-2	Is foetal testosterone related to autism-like behaviours? A study of dizygotic twins	45%	35%	9%	55%	1720	770
2008-004	Pathways to Affective Disorders: Interactions between Genes, Environment and Biological Mechanisms	77%	27%	44%	23%	3342	2570
2008-004-1	The Emotional Well-being project phase 2	83%	56%	14%	17%	81	67
2008-006	Genetics of Syncope and Breath Holding	73%	12%	60%	27%	2157	1567
2009-003	Prevalence and risk factors of Lower Back Pain - A Pilot Study	66%	36%	7%	34%	494	324
2009-004	Gut Number Sense in Twins	21%	6%	6%	79%	1997	429

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 2011, 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:

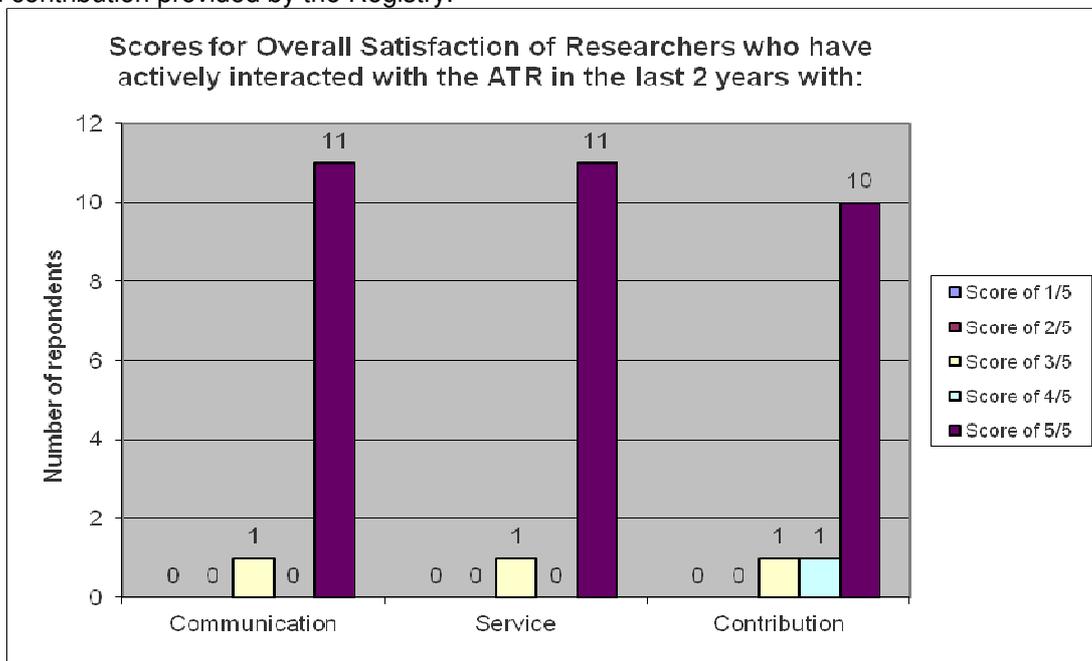
- (1) overall satisfaction with the researchers' communication with the ATR;
- (2) overall satisfaction with the services that the ATR provided; and
- (3) the value of the contribution that the ATR made to the overall research project

Responses were recorded as

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

We received feedback from 12 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 13**).

Figure 13. 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 making previously collected data and biospecimens available for re-use by other groups and to fostering new collaborations, 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 aims to build high-quality open source software information management system for the medical research community. The ATR contributes to both the design and development of The Ark's registry and study management components. 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.

Software modules to support recruitment, subject management, electronic questionnaires, and manage phenotypic and biospecimen data are currently in place. New modules to support comprehensive reporting and data extraction are currently in development.

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.

GOVERNANCE

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

ATR Management

As of 31 December 2011, 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 2011, 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 Otlowski (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 2011, the ATR developed 4 new roles: ATR Manager, ATR Study Coordinator, ATR Assistant Manager and a Marketing Officer. These additions ensure quality services are provided to the researchers and twin members. The ATR continues to employ a Project Support Officer 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 2011.

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 2011 towards a total of \$2,100.

The names of the ATR donors are listed below:

Virginia Rowland

Dr Sithi Sitharthan

Estate of Ellen Isabel Douglas

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.