

Annual Report
July 2008 - December 2009



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EXECUTIVE REPORT

Welcome to the 2009 Annual Report of the Australian Twin Registry (ATR)

This report provides a summary of the major activities, achievements, and research developments of the ATR during the 18 month period **1 July 2008 to 31 December 2009**. This reporting period covers the completion of the 2005-2009 Enabling Grant from the National Health and Medical Research Council (NHMRC) and makes the transition to a calendar-year timetable.

The ATR is pleased to announce its success in securing a 5 year (2010 – 2014) renewal of funding through the NHMRC Enabling Grant Scheme, at an increased level of \$500,000 p.a. The funding renewal was granted following an extensive review of Round 1 and 2 Enabling Grant Facilities by the NHMRC. The ATR's successful bid was based on its growth and performance over the previous grant period (2004-2009). The ATR excelled in the development and implementation of a clearly defined organisational structure and associated policies, and consistently increased the number and diversity of studies supported, and the number of ATR related publications.

During the period **1 July 2008 to 31 December 2009** the ATR actively supported 66 research studies, resulting in 245 mailouts to participants and 2,320 hours of telephone follow-up. Notably, 50 peer-reviewed articles based on ATR-related studies were published yearly in 2008 and 2009, accomplishing an important objective set by the ATR in the Enabling Grant application.

The ATR's Vision is to **“realise the full potential of research involving twins to improve the health and wellbeing of all Australians”**. In line with this vision, the Registry organised a successful meeting, *“2008 Statistical Genetics Short Course featuring Mendel”*, on 1-5 September 2008 in Coolangatta, Queensland. This course was planned by the ATR in response to requests from researchers for more hands-on tuition in twin research. Attended by 43 researchers (full attendance), this intensive course covered state-of-the-art statistical genetics methods for detection of genetic loci for complex traits (qualitative and quantitative). Seven lecturers, lead by Professor Kenneth Lange, travelled from the University of California Los Angeles to conduct the 5-day program. This was a landmark event for Australian genetic epidemiology that demonstrated the ATR's leadership in this aspect of medical research training.

Another highlight event of 2009 was the *3rd National Twins Plus Festival* held at the Taronga Zoo in Sydney on 14 March 2009. The event was hosted by the ATR and the Australian Multiple Birth Association (AMBA). The importance of multiples in research was highlighted and many families joined the ATR at the time of the festival. The number of attendees to this Festival was almost twice that of the previous Festival held in 2006 in Canberra, with more than 1400 in 2009 versus over 800 in 2006.

The ATR also organized together with the Garvan Institute of Medical Research a one-day meeting *“Research Involving Twins, an Invaluable Part of a Medical Researcher's Repertoire”* (Darlinghurst, Sydney, NSW; 13th March 2009), which focused on the involvement of twins in medical and health-related research. Twelve prominent speakers discussed their research with twins and offered insights into how twin research data have contributed to their overall research programme.

Overall, the 2008-2009 period has been filled with significant success in all areas of interest for the ATR, including research, funding and Registry growth.

ATR OVERVIEW

About the Australian Twin Registry

Established in the late 1970s, 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 2008-2009, the ATR maintained information on more than 36,000 sets of twins and higher order multiples (HOMS), and supported 66 active research projects 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 epidemiological 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 issues that affect Australians. Most recently, twin studies have started to play a vital role in the emerging search for epigenetic effects. Epigenetics studies investigate proteins and other molecules that bind to DNA, changing gene expression. Epigenetic effects have been linked to many diseases, such as 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. Originally covering the period 2004-2009, the grant has now been successfully renewed for a further 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.

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 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. The ATR's core functions are:

Core Function 1

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

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

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

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

Core Function 5

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

THE REGISTRY

Database

The Australian Twin Registry 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 and updates membership data to allow accurate record keeping and meaningful analysis of trends and results.

The new Registry database was launched in 2006 and it enables the ATR to more accurately collect reimbursement from researchers for work done on their behalf during 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 2009, the database held data on 73,194 individuals representing 36231 twin pairs, and 244 triplets.

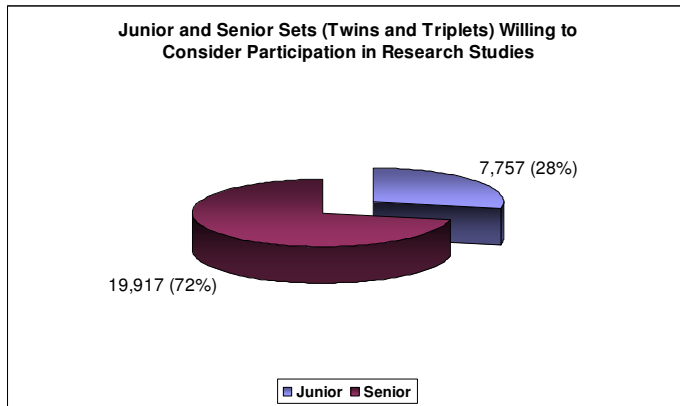
Members of the ATR are recorded under a specific status, depending on the currency of their contact details and individual preference for involvement in research activities. The majority of members enrolled in the period covered by this report (77%) are Active/Active, Active/ Questionnaire and Questionnaire/Questionnaire, indicating that they are willing to consider participating in research. The current status of members of the ATR is summarized in **Table 1**. An additional 7.3% of members' contact details require updating (recorded as Pending). At the end of 2009, 27,674 pairs of twins and triplets (**Figure 1**) were willing to consider involvement in research studies.

Table 1: Twin Pair Status Combination as of 31 December 2009. Top row details T1 (twin one) status, and left most column details T2 (twin two) status.

Twin Status	Active	Deceased	Duplicate	Lost	Lost (OS)	News-letter	Inactive	OS Temp	Question-naire	Pending	Total
Active	26903										26903
Deceased	319	848									1167
Duplicate	0	1	249								250
Lost	63	5	0	865							933
Lost (O/S)	3	0	0	2	11						16
Newsletter	83	25	0	4	0	197					309
Inactive	346	190	0	11	0	11	1893				2451
OS Temp	164	1	0	0	0	1	6	259			431
Question-naire	201	1	0	0	0	2	1	0	380		585
Pending	683	21	0	13	0	9	32	9	8	1827	2602
	28765	1092	249	895	11	220	1932	268	388	1827	35647

OS, overseas.

Figure 1. Junior and Senior Breakdown where status is Active/Active, Active/Questionnaire, and Questionnaire/Questionnaire as of 31 December 2009.



The current numbers of active and lost twin pairs by sex and zygosity and by location are shown in **Figures 2** and **3**.

Figure 2. Active and Lost Twin Pairs by Sex and Zygosity as of 31 December 2009.

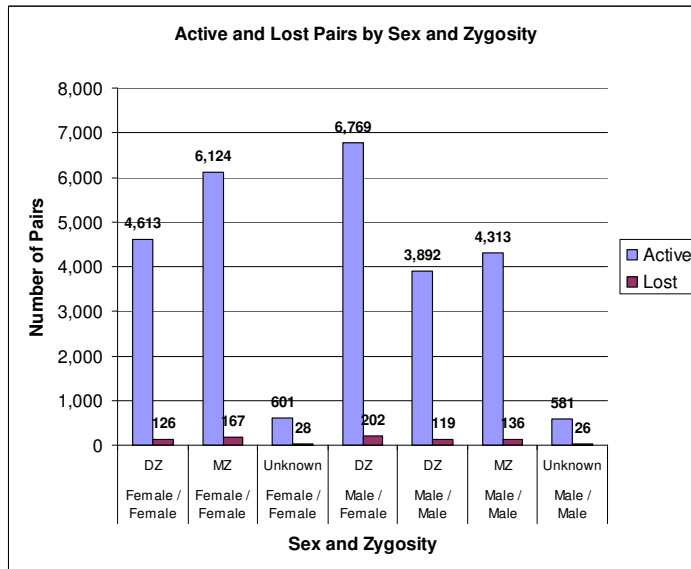
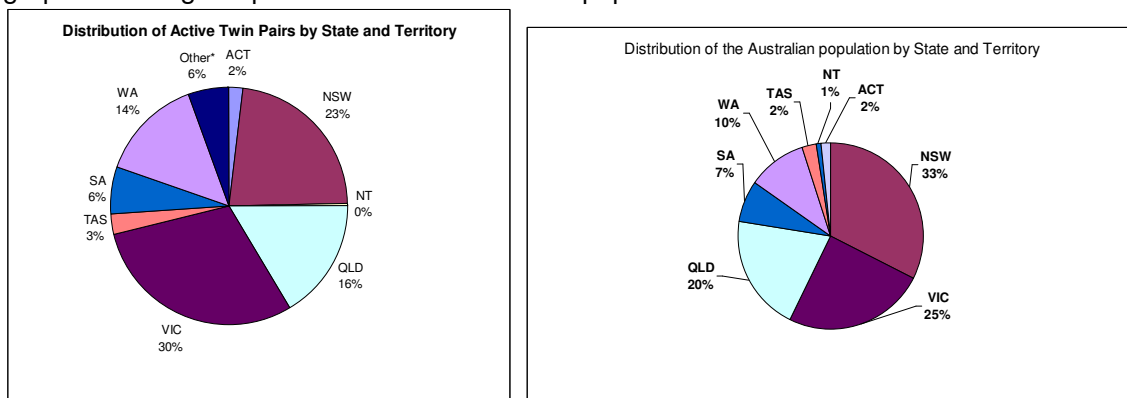


Figure 3. Active Twin Pairs Combination by Location as of 31 December 2009. For reference, graph on the right represents the distribution of population in Australia.



*Other refers to twins living in separate states.

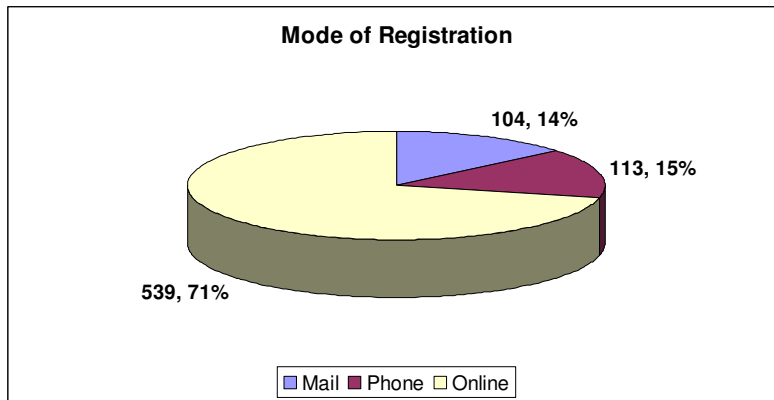
Recruitment

Continual recruitment of new twin members is vital to ensure the future viability of the ATR. The ATR's goal is to increase membership by 5000 over 5 years.

In the reporting period, 1 July 2008 to 31 December 2009, the ATR added membership details on 1560 twins and triplets; 756 pairs of twins (658 junior and 7 senior) and 16 pairs of triplets (14 junior and 1 senior). This represents an average recruitment of 1000 members per year, putting the Registry on track to achieve its 5 year membership goal.

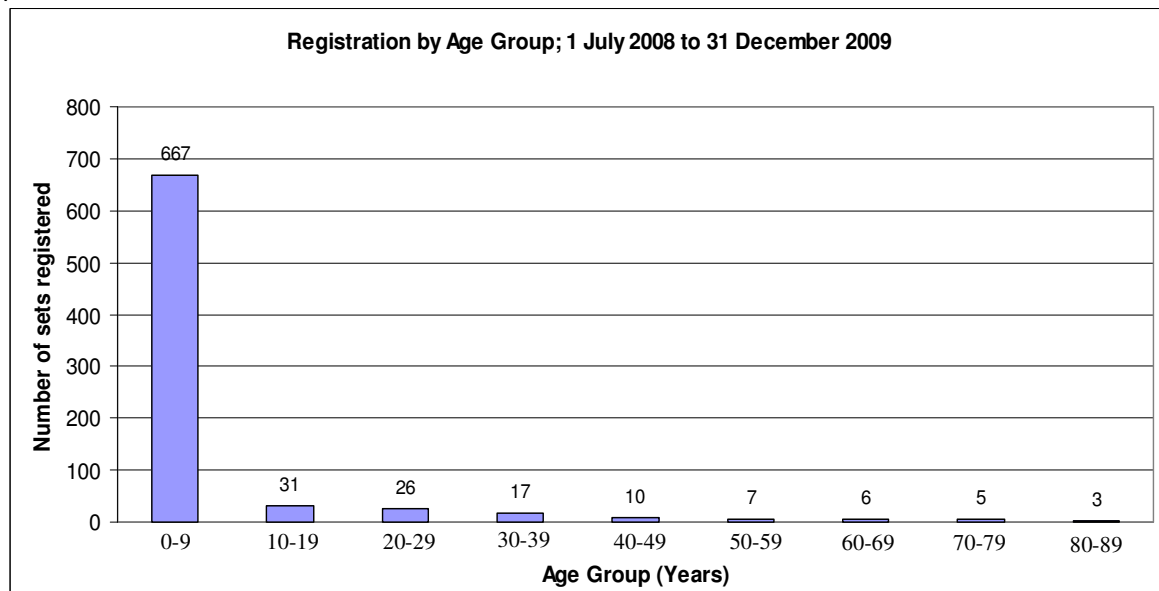
Approximately 71% of the new twin members used the internet to register with the ATR (**Figure 4**).

Figure 4. Mode of new registrations (twin pairs) for the reporting period of 1 July 2008 to 31 December 2009.



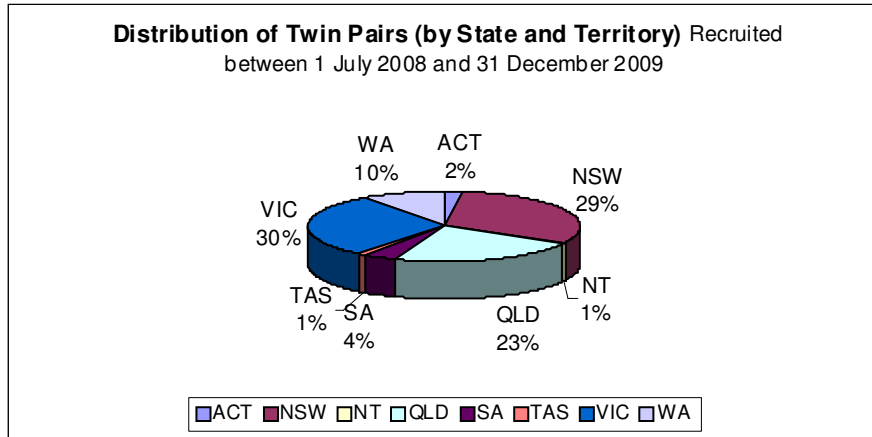
The majority of new members (86%; or 667 sets of twins and triplets out of 772 total) enrolling with the ATR during the reporting period were aged 0-9 years, a feature which has remained relatively consistent over a 20 year period (**Figure 5**).

Figure 5. Number of new registered sets (twins and triplets) by age range during the reporting period.



New registrants have come from all States and Territories in Australia. However, the majority reside in Victoria (30%), New South Wales (29%), and Queensland (23%) (**Figure 6**).

Figure 6. Distribution of twin pairs, by State or Territory, recruited during the reporting period. Note: triplets are excluded from the graph.



The numbers of new registrations by month during the reporting period 1 July 2008 – 31 December 2009 and by year since 1987 are represented in **Figures 7** and **8**. Both representations reflect the pattern of new registrations over a longer time period.

Figure 7. Number of new twin and HOMS pairs registered with ATR by month between January 2006 and December 2009. Green vertical line indicates start of the reporting period.

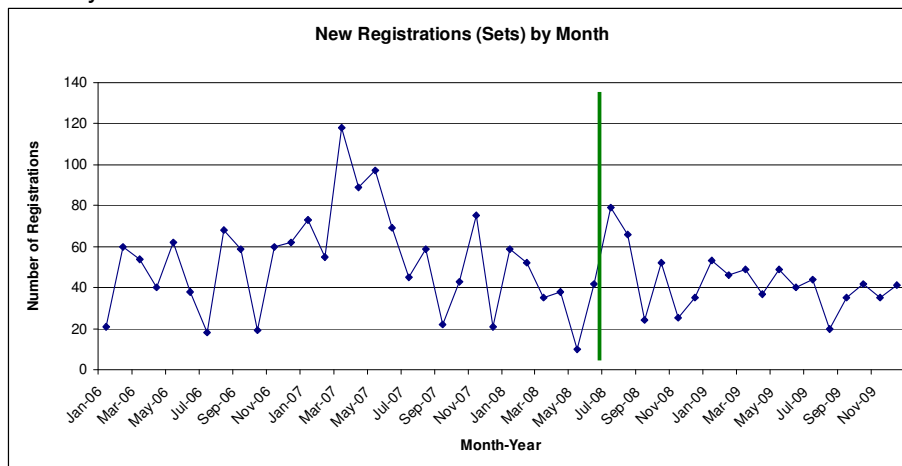
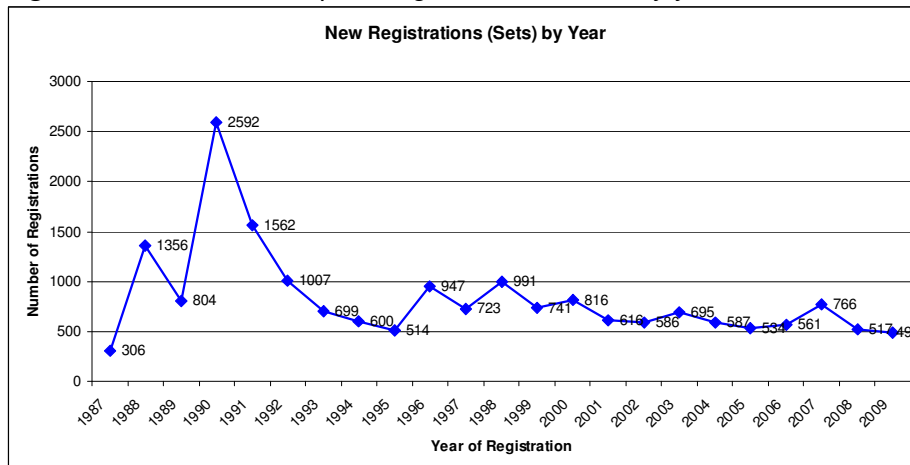
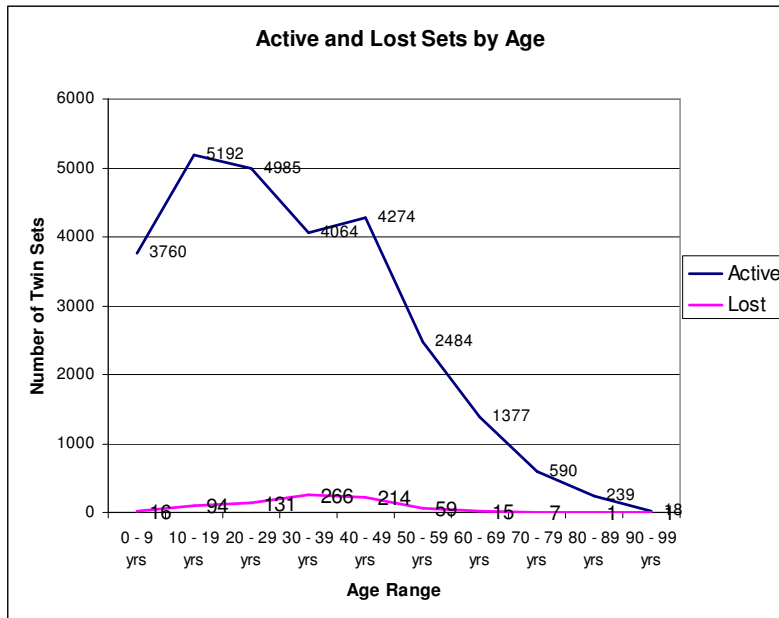


Figure 8. Number of new pairs registered with ATR by year since 1987.



The distribution of active and lost pairs of twins, across the Registry, is shown relative to the age groups of members in **Figure 9**.

Figure 9. Active and lost twin pairs by age as of 31 December 2009. Note: data on triplets are not included in the graph.



Currency and Accuracy of Membership Data

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

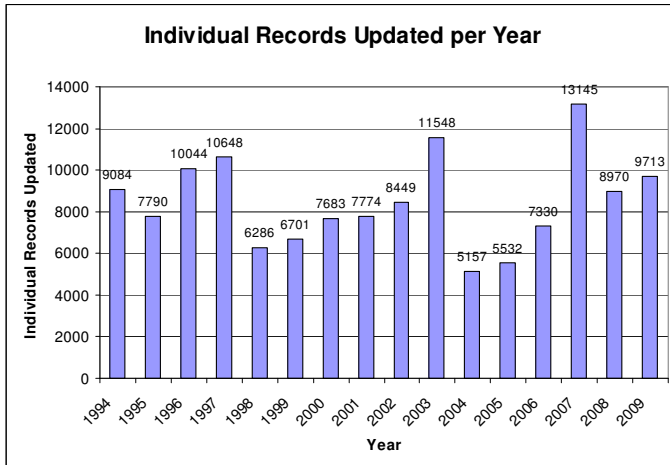
Although the *Twins* Newsletter is first and foremost a tool for communication with members, it also presents the largest opportunity available to assess the accuracy of member address data. Using *Twins* and other communication methods during the reporting period of 1 July 2008 and 31 December 2009, the Registry received 3368 return to sender (RTS) envelopes. At the end of 2009, 7.3% of members' contact details required updating (registered as "pending" in **Table 1**).

Record Updates

The ATR is aware that not all misdirected mail is in fact 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 individuals are recorded on the ATR database.

In the reporting period, 1 July 2008 to 31 December 2009, a total of 11,733 individual records were updated in the ATR database. These figures include 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 10**.

Figure 10. Numbers of individual records updated per year (1994-2009).



A significant increase in telephone follow-up for studies as well as the modifications to the database enabled us to reach these high numbers of updated individual records.

Website

During the current grant period, additional material was added to the ATR website, including information on:

- electronic access to the 2008 Annual Report
- ethical conduct of research

Substantial efforts were devoted to directing web traffic to online surveys for research studies.

See www.twins.org.au for more information.

Media Activities

Through the 2008 *Twins* Newsletter, the ATR instigated a Media Mailing List, which enables the ATR to circulate media enquiries and opportunities to those members who have expressed an interest in receiving such information.

In 2008-2009, the ATR used this mailing list to assist in circulating information for eight events; six television shows, one science/technology article and one art project.

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.

Activities for WATCH and WATR during 2008-2009 were focused on securing the existing data with the Western Australia Genetic Epidemiology Resource (WAGER), an NHMRC Enabling Facility, which aims to support data management and storage for epidemiology projects across Australia. WATR and WATCH data were successfully migrated to this facility.

Acquisition of new registrations was halted due to significant staffing changes in our Western Australian team. Jan Hansen, our WATCH Coordinator was diagnosed with ovarian cancer in 2009 and with much sorrow, passed away in late 2010. Jan was tireless in her dedication to WATCH to the end and will be sorely missed. WATR Director, Professor Lyle Palmer, accepted a position at the Ontario Institute for Cancer Research, and following Professor Palmer's move, Jessica Lee, WATR Coordinator, took up a new position in the Data Linkage Branch, Department of Health Western Australia.

Given the significant changes to the major drivers of the WATCH / WATR group, ATR management is now working on decisions regarding the long term maintenance of the data.

match report

As an integral part of the ATR, 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.

As reported in the 2008 Annual Report, match moved from being administered through the Department of Paediatrics, based at the Royal Children's Hospital, to the Centre for MEGA Epidemiology, in the School of Population Health, within the University of Melbourne.

Activities in 2008-2009 focused on critically reviewing the progress of the project;

- ATR management and the match team concluded that the administration of some portions of the project were overly time and resource consuming at this stage, and subsequently paused collection of maternal and cord blood. Investigation of buccal cell collection is underway to provide biological samples for the project.
- Public enquiries regarding match were channeled through the ATR free-call number to provide additional Research Assistant support, which resulted in more streamlined communication regarding the relationship between the ATR and match.
- The information booklet developed as part of match is now offered to all women who are pregnant with twins regardless of their involvement with match; this has resulted in an increased recruitment to the ATR of women who decline participation in the match project, but who remain interested in other research projects.

During this time the match Coordinator, Dr Supriya Raj commenced maternity leave and the ATR Senior Project Officer, Kim Dorrell acted as match coordinator.

Match is now running successfully at thirteen hospitals in and around Melbourne (Royal Womens, Francis Perry, Mercy, Monash, Jessie McPherson, Cabrini, Freemasons, St Vincent's Private, William Angliss, Sunshine hospitals, Box Hill, Peninsula Health Frankston and Barwon Health Geelong).

Recruitment of match participants continued in 2008-2009 with 57 participants registered (2 have since withdrawn).

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

SCIENTIFIC MERIT

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; studies which are involved in active recruitment; and studies that have completed or paused recruitment but may require additional support for follow-up and clarification with members.

The Registry has experienced a gradual rise in the rate, range, size and sophistication of studies. A complete count of all studies, by status, as of 31 December 2009, is shown in **Table 2**.

Table 2: Studies by Status 2009.

Study Status	Number
Discussion	4
Expression of Interest (Awaiting funding)	9
ACTIVE - RECRUITING	29
ACTIVE - PROTOCOL CHANGE/AMENDMENT	1
ACTIVE - DATA ANALYSIS	24
ACTIVE - ONGOING PROGRAM	13
ACTIVE - WRITING UP	8
COMPLETED	71
ABANDONED	8
Full Application	*
Ethics	*
Approved – awaiting recruitment start	*
ON HOLD	6
UNKNOWN	5
TOTAL	178

**, at the time of writing this Annual Report all these studies have moved into the Active - Recruiting category.*

Researcher reports

The **Researcher Reports** provided by the researchers and associated staff summarise the current activities undertaken by each study active in the current reporting period (1 July 2008 to 31 December 2009), major achievements for this period and future plans. These reports are included in [Appendix 1](#) of this Annual Report.

Publications

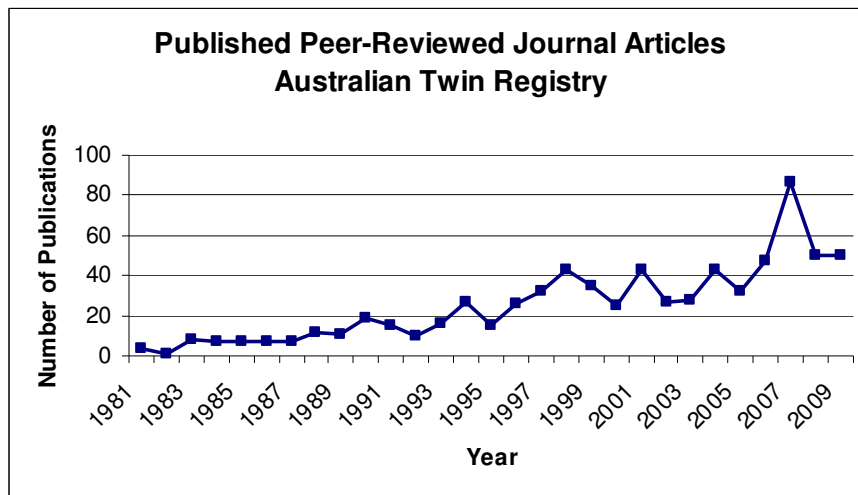
An important measure of the output of the ATR is the number of publications arising from studies supported by the facility. An important goal set by the ATR in the Enabling Grant was to increase the number of peer-reviewed articles to 50 per year.

In both 2008 and 2009 50 articles were recorded. Since 1981, **710** peer-reviewed publications and **503** conference proceedings have arisen from ATR supported projects (**Table 3** and **Figure 11**). A listing of publications in 2008-2009 can be found in [Appendix 2](#).

Table 3: Publications Arising from ATR Supported Projects Since 1981.

	Completed	In press	Submitted	In preparation
Book	2	1		
Book Section	57	6	1	1
Published Abstracts				
Conference Proceedings	503			
Peer Reviewed Publications	710	17	2	14
Thesis	18			
Reports	7			
Newspaper Articles	19			
Magazine Articles	5			

Figure 11. Number of articles published per year since 1981.



Meetings and Conferences

- *Twins Plus Festival*

The *Twins Plus Festival* was held on 14th March 2009 at the scenic Taronga Zoo in Sydney. The festival was a fantastic celebration of 'multiplicity', with more than 1400 people attending. There were plenty of festivities to keep everyone amused, including face painting, animal exhibits and competitions. Twins, triplets and quadruplets had the unique opportunity to mingle with other multiples and their families. The ATR had a team of staff attend, including the Director, Professor John Hopper, the Deputy Director, Dr Debra Foley, and the head of ATR's Advisory Board, Mr Vincent Pollaers (who is a twin himself).

During the festival, twin members were invited to participate in a few research studies: a national collaborative study looking at how genes and the environment affect emotional

development, called the 'The Emotional Well-being Project' (The University of Sydney); a behavioural study on face recognition and related topics 'Face and object processing in adults, children, and infants', (The Australian National University), and 'The Older Australian Twins Study (OATS)' (Prince of Wales Hospital, Randwick NSW), which looks at the genetic and environmental influences that may affect memory and brain health as we get older.

- *NHMRC: "Transparency and Conflict of Interest workshop" (Canberra, ACT; 2nd June 2009)*

In June 2009, NHMRC launched a new series of interactive workshops aimed at stimulating discussion in the research sector and wider community on issues of national importance to health and medical research. The workshops also provide NHMRC with the opportunity to explore opinion across the sector and assist in shaping the agency's advice as well as identifying emerging issues of concern.

The inaugural workshop focused on transparency and conflict of interest. The workshop included speakers from pharmaceutical and biotech industries, clinical researchers and publishers. Professor John Hopper, Director of ATR, participated in the workshop.

- *The Garvan Institute of Medical Research: "Research Involving Twins, an Invaluable Part of a Medical Researcher's Repertoire" (Darlinghurst, Sydney, NSW; 13th March 2009)*

This one-day meeting organized by the ATR at the Garvan Institute emphasized the involvement of twins in medical and health-related research and addressed ways in which involving twins and various analytic methodologies can stimulate research across a wide range of disciplines.

The event was aimed at early to mid career researchers who did not necessarily have previous experience in studies involving twins, and senior researchers with capacity to launch twin studies. The programme featured 12 prominent speakers discussing the different ways twins have been incorporated in their research and how the inclusion of twins and the special insights twin data provides have contributed to their overall research programme.

ATR Community Updates

Researcher Training

The ATR undertakes annual activities to facilitate the training and development of Australian researchers in the methodology and practice of studies involving twins. These activities include presentations at international and national conferences, and the coordination of workshops and seminars aimed at new and existing researchers. This process is considered fundamental to ensure the vitality and quality of twin research using the ATR.

During the period July 2008 - December 2009 the following twin workshops were conducted:

- *2008 Statistical Genetics Short Course featuring Mendel*

In response to requests from researchers new to the field of research involving twins, the ATR convened an intensive short course in 1st – 5th September 2008, in the 'Twin Towns' of Coolangatta/Tweed Heads, Southern Queensland.

This short course covered state-of-the-art statistical genetics methods for detection of genetic loci for complex traits (qualitative and quantitative), and included hands-on computer exercises using statistical genetics computer programs, particularly Mendel, SimWalk, and

FBAT. Seven lecturers, headed by Professor Kenneth Lange, from the University of California Los Angeles, were invited to conduct the 5-day program.

- *GeneMappers 2009; 7th Australian Human Gene Mapping Conference*

The 7th GeneMappers Conference was held in the Blue Mountains, NSW April 14-17th 2009. The convenors, Professor Peter Schofield and Dr Juleen Cavanaugh, organized a diverse and stimulating program that described current gene mapping and other approaches to characterising genetic risk factors for complex diseases including arthritis, ataxia, bipolar disorder, cancer, Crohn's disease, diabetes, dementia, heart disease, osteogenesis imperfecta, migraine, multiple sclerosis, and schizophrenia. Sponsors included the Australian Twin Registry, The Prince of Wales Medical Research Institute, Illumina, Applied Biosystems, Genetic Repositories Australia, Eppendorf South Pacific, Millennium Science, Geneworks, Sequenom, Supamac, Brain Sciences UNSW and DNA Genotek.

Research Travel Grant Scheme

During this reporting period, rounds 6 and 7 of the Research Travel Grant Scheme have been put on hold due to renewal of the NHMRC Enabling Grant. As this grant was successfully renewed for the period 2010-2014, the scheme resumes in 2010.

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

PARTICIPATION

Mailouts

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 the period 1 July 2008 – 31 December 2009, **245** mailouts were conducted, with a total of **33,872** letters sent.

Table 4 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 4: Number of mailouts and total letters by study.

Study ID	Study Name	Number of Mailouts		Total Letters	
		2008	2009	2008	2009
98-001-1	Genetics of Reading Ability: Extension	1		29	
2002-002	A Study of the Potential Causes of Psychosis in a Twin Sample	1		100	
2002-004-3	Solving the Jigsaw! Understanding Biological and Environmental Effects on ADHD	12		1607	
2004-003	The Effect of Anti-Epileptic Medications on Bone Mineral Density, Balance and Fracture Risk - A Twin and Sibling Study	1		14	
2005-002	Molecular Genetics of Inattention in Australia	9	3	1304	210
2005-003	The Twin Study of Brain Ageing and Cognition	9	9	756	646
2005-003-1	The Twin Study of Brain Ageing and Cognition - Phase 2	2	3	196	229
2006-001	Cannabis and Other Illicit Drug Use: A Twin Study	22		2506	
2006-001-1	Cannabis and Other Illicit Drug Use: A Twin Study: Phase 2		5		98
2006-004	Genetic and Environmental Factors in Invasive Cervical Cancer: A Twin Study	4	28	600	2818
2007-003	The Heritability of Rational (Analytical) versus Eperiential (Intuitive) Reasoning: A Pilot Study	4	6	3600	600
2007-004	Role of Genetic and Environmental Factors in Atrial Fibrillation	6	7	600	1178
2007-005-1	Compromised or competent? A longitudinal study of twin children's social competencies, friendships and behavioural adjustment: Phase 2		1		66
2007-005-2	Compromised or competent? A longitudinal study of twin children's social competencies, friendships and behavioural adjustment: Phase 3		6		900
2007-006	Prenatal Hormones and Mild Traits of Autism: A Twin Study	6		1760	
2008-001	Effect of Menopause on the Structure of Bone	19	1	1464	108
2008-002	Genes, Diabetes Mellitus and Dementia	7		356	
2008-003	The Genetic and Environmental Etiology of Second Language Acquisition	1		4031	
2008-004	Pathways to Affective Disorders: Interactions between Genes, Environment and Biological Mechanisms		36		2812
2008-005	Face Recognition in Twins	5	13	1200	2600
2008-006	Genetics of Syncope and Breath Holding		12		1184
2009-002	Twin Satisfaction Survey		5		280
2009-005	Garland media launch		1		20
TOTAL		245		33,872	

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 the ATR for **19** out of **29** 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 5**. Please note these figures do not include telephone calls and hours spent tracing twins who have moved 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 5: Number of calls and hours spent on the calls by the ATR staff (1 July 2008 – 31 December 2009)

Study ID	Study Title	# Calls	# Hours
98-001-1	Genetics of Reading Ability: Extension	25	3.5
2002-004-3	Solving the Jigsaw! Understanding Biological and Environmental Effects on ADHD	1,610	165.14
2004-003	The Effect of Anti-Epileptic Medications on Bone Mineral Density, Balance and Fracture Risk - A Twin and Sibling Study	14	2.75
2005-002	Molecular Genetics of Inattention in Australia	2,537	271.85
2005-003	The Twin Study of Brain Ageing and Cognition	680	126.65
2005-003-1	The Twin Study of Brain Ageing and Cognition - Phase 2	227	47.25
2006-001	Cannabis and Other Illicit Drug Use: A Twin Study	2,150	296.63
2006-001-1	Cannabis and Other Illicit Drug Use: A Twin Study - Phase 2	146	25.35
2006-004	Genetic and Environmental Factors in Invasive Cervical Cancer: A Twin Study	3,355	302.4
2007-003	The Heritability of Rational (Analytical) versus Eperiential (Intuitive) Reasoning: A Pilot Study	785	85.5
2007-004	Role of Genetic and Environmental Factors in Atrial Fibrillation	722	96.75
2007-005-1	An Investigation into the Nature of Growing Pains	144	26.4
2007-006	Prenatal Hormones and Mild Traits of Autism: A Twin Study	57	5
2008-001	Effect of Menopause on the Structure of Bone	1,116	127.86
2008-002	Genes, Diabetes Mellitus and Dementia	115	17
2008-003	The Genetic and Environmental Etiology of Second Language Acquisition	439	49.4
2008-004	Pathways to Affective Disorders: Interactions Between Genes, Environment and Biological Mechanisms	3,295	433.4
2008-005	Face Recognition in Twins	1,151	116.45
2008-006	Genetics of Syncope and Breath Holding	762	120.75
Total		19,330	2,320.03

Response Rates

The overall response rate 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' 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 6** 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 18-40 years old have the highest 'NR (*Nil Response obtained*)' and '*Negative Response*' rates and are the most difficult group for which to maintain current contact information. Negative response rates 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 6: Study response statistics to date for most active studies (recruiting and ongoing).

Study ID	Total Response Rate	Positive Response Rate	Negative Response Rate	NR Response Rate	Total Pairs Approached	Total Responses	Active Study Status
01	100%	56%	0%	0%	9	9	Recruiting
2010-001	45%	24%	15%	55%	300	135	Recruiting
2010-004	53%	20%	22%	47%	45	24	Recruiting
94-005-2	91%	46%	40%	9%	2656	2420	Recruiting
96-001	49%	16%	31%	51%	1006	495	Ongoing program
96-009	69%	31%	30%	31%	1211	830	Ongoing program
97-001-3	50%	15%	31%	50%	377	187	Ongoing program
98-001-2	70%	69%	1%	30%	213	150	Recruiting
98-006	0%	0%	0%	100%	1873	5	Ongoing program
2002-004-3	75%	60%	15%	25%	1607	1200	Recruiting
2003-001	86%	35%	43%	14%	951	817	Ongoing program
2004-001	82%	68%	14%	18%	485	398	Ongoing program
2004-003	41%	1%	40%	59%	3543	1463	Recruiting
2004-004	75%	4%	69%	25%	3036	2268	Recruiting
2005-002	77%	35%	39%	23%	1337	1030	Recruiting
2005-003	97%	46%	50%	3%	971	943	Recruiting
2005-003-1	100%	76%	24%	0%	212	212	Recruiting
2006-001	82%	39%	35%	18%	3925	3230	Recruiting
2006-001-1	92%	0%	17%	8%	98	90	Recruiting
2006-004	83%	40%	31%	17%	4157	3447	Recruiting
2007-003	28%	6%	16%	72%	2100	579	Recruiting
2007-004	78%	36%	40%	22%	936	726	Recruiting
2007-005-2	21%	8%	12%	79%	1701	350	Recruiting
2007-005-3	0%	0%	0%	100%	32	0	Recruiting
2007-006	28%	2%	12%	72%	1072	295	Ongoing program
2007-006-2	44%	35%	9%	56%	1720	762	Recruiting
2008-001	91%	44%	46%	9%	615	559	Recruiting
2008-002	96%	42%	51%	4%	177	170	Recruiting
2008-003	42%	10%	32%	58%	4000	1671	Recruiting
2008-004	77%	28%	44%	23%	2962	2287	Recruiting
2008-004-1	81%	48%	8%	19%	48	39	Recruiting
2008-005	29%	12%	10%	71%	1900	544	Recruiting
2008-006	73%	12%	60%	27%	2154	1564	Recruiting
2009-002	24%	9%	2%	76%	140	34	Ongoing program
2009-002-1	56%	21%	10%	44%	250	140	Recruiting

Study ID	Total Response Rate	Positive Response Rate	Negative Response Rate	No Response Rate	Total Pairs Approached	Total Responses	Active Study Status
2009-003	65%	32%	7%	35%	493	322	Recruiting
2009-005	90%	80%	10%	10%	10	9	Recruiting

Adverse Effects and Complaints

The ATR takes any complaint from members seriously and endeavors to promptly resolve the issue presented. The ATR requires all adverse effects and complaints to be communicated to ATR Management. During the reporting period, two ATR members filed complaints to the Registry. They were discussed in a timely manner and both ended with positive resolutions.

VALUE-ADD

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

VALUE-ADD

Quality Improvement Project

In response to the NHMRC's requirement for stakeholder feedback, the ATR has 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.

As part of this QA Program, during the reporting period (1 July 2008 to 31 December 2009), the ATR undertook a Twin Member Satisfaction Survey in mid 2009, an Annual Researcher Satisfaction in mid November 2009, and a Researcher Satisfaction Survey—comparison between Phase 1 (2006) and Phase 2 (2009).

Twin Member Satisfaction Survey 2009

A total of 4 mail-outs were conducted utilising the delivery and response methods listed in **Table 7**. We received 50 completed surveys out of 280 invitations to participate – a positive response rate of 17.8%.

Table 7. Numbers of surveys received (by mail-out type) and percentage response rates.

Mail-out type	Surveys received	% Positive response rate
Paper Based Survey	18	22.5
Paper Response Form	7	12.5
Pre-emptive Telephone Call	11	22
Email Link	14	28
TOTAL	50	17.8% overall

The feedback from our responding twin members was overwhelmingly positive, with very few negative comments received. The key findings extracted from the surveys are listed below:

- The majority of respondents joined the ATR because they wanted to contribute to scientific research with most being only a member of the ATR and not other health related registries.
- General satisfaction with membership and alignment with members expectations is high (61.7% Very Satisfied / 25.5% Somewhat Satisfied / 12.8% A little Unsatisfied / 0% Very Unsatisfied). Dissatisfaction seems to stem from lack of opportunity to be involved / too few invitations to participate, lack of personal feedback after studies and issues with lost contact details resulting in a time period of no contact.
- Telephone contact with members has been overwhelmingly positive.
- Members who responded would like to be contacted with more study invitations at a higher frequency than is currently provided.
- Most respondents indicated that they enjoyed participating in volunteer activities in general and had done so at some time in their life. Most participate in surveys when approached, but are selective about the topic. Most are happy to participate in studies

with more than a 'phone only' component, and most like the idea of web surveys and are comfortable using the Internet.

- Almost 60% of respondents recall receiving the latest *Newsletter*, with most stating that they read it "cover-to-cover". Suggestions for improvement included more information on each study conducted and information on twinship in general.
- Only 34% of respondents have ever visited the ATR website (of these, some had only visited the site due to this survey). All but one visitor to the website found what they were looking for.
- Awareness of the *Twins Plus Festival* was low with only 34% of respondents knowing about either or both festivals; only 3 surveyed had attended either one or both festivals. The majority of respondents felt they would consider attending a festival in their state, with only 38% considering attending if it were held in a different state.
- A series of detailed questions were asked regarding opinions on the re-use of research data. The great majority of respondents agreed that re-use of de-identified data by the original research group was "OK", even when utilised for a different (but related) purpose than originally intended, and the original participants were not contacted. Upon further exploration, most respondents felt "OK" about data being managed by the ATR for use by different research groups. Respondents commented that times when it would not be "OK" to re-use data include: *a)* any profit based activities, *b)* if the research was not health based, *c)* if participants were somehow able to be identified, and *d)* if the data was of a socially personal nature (example given was psychiatric surveys and "personal information") or the research was controversial. The majority of respondents indicated that if consent was provided by parents when the child was a minor, then re-consent of the twin as an adult should be sought.
- 85% of respondents recalled participating in at least one study, with most being able to recall the topic of research. Most experiences were positive. Negative experiences cited were length of study and difficulties/reluctance in blood sampling, though these experiences would not deter the respondent from participating in further studies.

Annual Researcher Satisfaction Survey 2009

The survey, which was administered as part of the Annual Progress Report submitted by researchers, asked the following four questions:

1. Please rate your overall satisfaction with your communication with the ATR in the past 18 months (1 - Very Dissatisfied / 2 - Dissatisfied / 3 - Neutral / 4 - Satisfied / 5 - Very Satisfied)
2. Please rate your overall satisfaction with the services that the ATR has provided in the past 18 months (1 - Very Dissatisfied / 2 - Dissatisfied / 3 - Neutral / 4 - Satisfied / 5 - Very Satisfied)
3. Please rate the value of the contribution that the ATR has made to your overall research project (1 - Unsatisfactory / 2 - Satisfactory / 3 - Good / 4 - Very Good / 5 - Excellent)
4. Please comment on any other problems, difficulties, or issues which you think need to be brought to the attention of the Registry. We also welcome any other comments or ideas you have to assist us to improve our service to researchers.

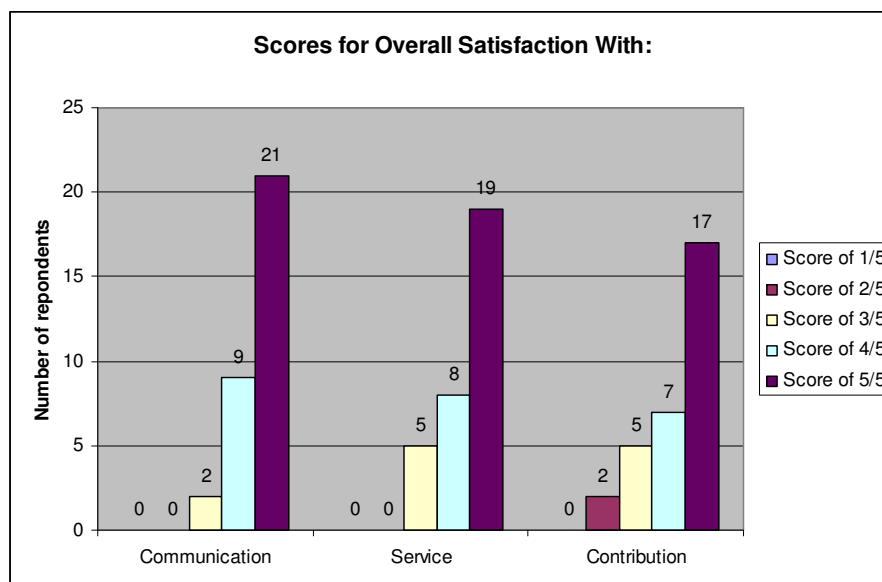
Each question also provided the opportunity for researchers to elaborate in a free text field.

A total of 34 completed reports were received. Overall, the survey found that researchers are very satisfied with the communication and service provided by the ATR and the contribution the ATR has made to their project. Scores for overall satisfaction by number of respondents are shown in **Table 8** and **Figure 12**.

Table 8.

Summary Scores for Overall Satisfaction With:											
Rating	1		2		3		4		5		Response Count
Communication	0	0%	0	0%	2	6%	9	28%	21	66%	32
Service	0	0%	0	0%	5	16%	8	25%	19	59%	32
Contribution	0	0%	2	6%	5	16%	7	23%	17	55%	31

Figure 12. Numbers of respondents providing satisfaction scores for communication, service and contribution.



Researcher Satisfaction Survey—comparison between Phase 1 (2006) and Phase 2 (2009)

The ATR surveyed active researchers in 2006 to ascertain satisfaction with services provided by the Registry. Thirty percent (47/156) of researchers who had submitted an application to use the services of the ATR prior to September 2006 completed this satisfaction survey (Phase 1, 2006). The ATR repeated this survey in April 2009 with new researchers who applied to use the ATR after September 2006 (Phase 2, 2009). Seventy-three percent (8/11) of eligible researchers completed the second researcher satisfaction survey. Repeating the survey was a useful measure of the change in researcher satisfaction over time, especially considering the growth and development of the ATR during that period.

Half of the respondents to the first survey and 75% of respondents to the second survey were senior researchers, i.e. Chief or Principal Investigators.

Almost three quarters of respondents (72%) to the first survey reported communicating with the ATR by email; just over half (57%) communicated by phone. The first survey identified telephone calls as an important method of contact with ATR to ensure a clear understanding of the researchers needs, and to set reasonable expectations. In the second survey all respondents had contacted the ATR by phone, and this was considered especially helpful in the early stage of study development.

Communications Rating

The Phase 1 survey indicated that overall researcher satisfaction with ATR communications was high, but that researchers had experienced frustration regarding ATR processes and policy.

The Phase 2 mean score of all ratings was 5.9/6.0, an increase in satisfaction by 0.7 points. Comments received indicate that the service provided by the ATR is of a high calibre.

Aspects of Work Involved with the ATR

The areas of the researcher's work involving the ATR in 2009 were similar to those reported in 2006, including assistance with preparation of grants and ethics applications, and responding to reviewer's comments. Phase 2 respondents indicated an increased involvement of the ATR in assisting with the design/conceptualising of their study and/or preparation of applications (up from 40% in Phase 1 to 75% in Phase 2), and in developing approach letters/information sheets/consent forms (up from 51.1% in Phase 1 to 100% in Phase 2). The ATR has improved its contribution and its communication in the early stages of research projects.

Overall Value of ATR Contribution Rating

The mean score of ratings on overall value of the ATR's contribution to researcher's work was 5.1/6.0 in Phase 1. Respondents regarded the value of the ATR's contribution to their work very highly, with over three quarters (77.5%) rating it 5 or 6 out of 6. The Phase 2 survey responses showed a mean rating of 5.9/6.0, an increase of 0.8 points, with only one respondent rating the item less than 6 (5.5 out of 6). This is an overwhelmingly positive result with all new researchers placing a very high value on the contribution that the ATR made to their work.

Value of Feedback Rating

A more specific question as to the value of ATR feedback provided to researchers during the application process itself was asked. In Phase 1 the mean rating was 4.7/6.0. Two thirds of respondents gave a rating of either 5 or 6 out of 6. The Phase 2 survey mean rating was 5.7/6.0, an increase of 1.0 on the previous score, and seven eighths rated the feedback at 5 or 6 out of 6.

Level of Response and Participation

The Phase 1 respondents gave a mean rating 3.9/6.0 when asked to describe the level of their satisfaction with twin participation in their study. One quarter of all Phase 1 respondents rated this at just 3 or below. In fact, twin participation in studies was the activity rated lowest in the Phase 1 survey. It was noted by the report author that the majority of negative sentiment in this area stemmed from researcher's "perception of what is realistic".

The Phase 2 survey mean rating of the level of their satisfaction with twin participation in their study was 4.5/6.0, indicating an increase of 10% (0.6 points). However, verbatim comments clearly acknowledged that limitations of the study design large influenced the level of satisfaction. These comments are quite in contrast to some comments from 2006, and specifically highlight that the ATR has been able to more clearly communicate both the limitations of its own area of influence, the issues around tight exclusion/inclusion criteria for studies, and that in the end, twin participation is a matter for the members themselves and not something that the ATR can unduly influence. **The focus has been shifted away from the perception that the ATR is at fault for lack of participation, to one where the realities of recruiting highly specific volunteer cohorts are clear.** In addition, comments received indicate that participation was greatly influenced by the project budget.

The ATR now invests much energy into the early phase of study development with researchers, and a specific focus has been made on clarifying expectations and working with researchers as a team to forward the goals of the study. This approach seems to have dissipated frustration, and allowed a clearer understanding of the influencing factors that affect participation.

Managing demands

Researchers were asked about the best methods to manage demands for time and participation upon twins. Phase 1 survey respondents considered that better management of the twin approach process and of tracking the number of studies twins were invited to, and offering incentives could alleviate the demand on twins.

It is clear from both the Phase 1 and Phase 2 surveys that researchers support the role that the ATR plays in monitoring the number of times an individual twin is asked to participate in studies.

This indicates a significant support for ATR's role as an advocate for its twin members.

Careful consideration of the areas of research, and perhaps encouragement of studies that are about twins and twinship, are also mentioned. This suggestion is somewhat difficult for the ATR to have a direct influence on, as while we are able to encourage researchers to work up study designs involving twins, we have limited ability to assist researchers in successfully accessing grant funds. Nevertheless, the ATR has been a strong advocate of such research over the last 30 years.

Events/Activities

Questions regarding the researcher's interest in Events and Activities indicated that the *Twins Newsletter*, Twin Researcher Network and ATR website still rate highly. Interest in researcher training has decreased, although this could be a consequence of the higher proportion of senior level researchers responding to the Phase 2 survey.

Biobank / Archive

Interest in the creation of a research archive has decreased slightly from 5.3/6.0 in Phase 1 to 4.9/6.0 in Phase 2. Comments received in the Phase 2 survey indicate researcher's growing awareness of the issues surrounding privacy, intellectual property and copyright. None of the researchers surveyed in Phase 2 indicated that a Biobank would be applicable to the data collected during their specific ATR project.

In conclusion, the results of these surveys indicate that the ATR has improved its communication to researchers and has succeeded in reducing frustration regarding turn-around time on applications and participant involvement. It is clear that the effort expended on more direct communication and increased buy-in by the ATR into the design and development of studies has benefited both the ATR and researchers.

ATR Data Index Project

A goal of the Registry is to make previously collected data and biospecimens available for re-use by other groups and to fostering new collaborations wherever possible. As a step towards fulfilling these aims, in 2008, the Registry devised a web-based, searchable index of all previous studies conducted via the ATR.

Accessible at http://www.twins.org.au/study_index/BasicSearch.php the index, which was launched in 2009, enables users to conduct searches based on keywords and specific criteria. A list of all previous studies matching the search parameters will be returned, including:

- ATR study ID number
- Study title
- Investigator/s
- Host institution/s
- Year/s study conducted
- 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 are being systematically reviewed and checked against existing hard copy files to ensure the most complete listing possible.

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

GOVERNANCE

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

GOVERNANCE

ATR Management

As of 31 December 2009, the ATR Management comprised:

- Prof John Hopper, Director, Australian Twin Registry; NHMRC Senior Principal Research Fellow; Director (Research), Centre for Molecular, Environmental, Genetic and Analytic (MEGA) Epidemiology, University of Melbourne
- Dr Debra Foley, Deputy Director, Australian Twin Registry; ORYGEN Research Centre
- Prof. Nick de Klerk, Director, Western Australia Twin Child Health (WATCH)
- Dr Ruth Morley, Deputy Director, Australian Twin Registry; Senior Research Fellow, Department of Paediatrics, University of Melbourne
- Prof Lyle Palmer, Director, Western Australian Twin Registry (WATR) - resigned
- Mr Vincent Pollaers, Chair, Advisory Board
- Jenny Boadle, ATR Coordinator
- Kim Dorrell, ATR Senior Project Officer
- Emily England, ATR Senior Project Officer
- Supriya Raj, Coordinator, *mothers and their twin children (match)*
- 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

Currently, the Advisory Board members are:

- Mrs Ann Marie Harli (AMBA Representative, Victoria)
- 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)
- Dr. Keith Horsley (Australian Institute of Health and Welfare, Retired)
- Professor Margaret Otlowski (University of Tasmania, Tasmania)
- Mr Vincent Pollaers (Twin Representative, Chair, New South Wales)
- Professor David Ravine (Western Australian Institute of Medical Research, Western Australia)
- A/Professor David Whiteman (Queensland Institute of Medical Research, Queensland)

Ex-officio:

- Professor John Hopper (Director, ATR, University of Melbourne)
- Dr Debra Foley (Deputy Director, ATR, ORYGEN Research Centre)

ATR Staff

The ATR is administered through The University of Melbourne, within the Centre for MEGA Epidemiology, in the School of Population Health. The ATR currently employs two full time (Coordinator and Project Support Officer) and two part time (Senior Project Officer) administration staff; five casual staff (equivalent of 1.6 EFT), and a part time Database Manager. The ATR also provides an honorarium towards a part time Deputy Director.

Dispute Resolution Process

The Dispute Resolution Process is approved by the Advisory Board to enable impartial and transparent management of any dispute arising between the ATR and stakeholders.

ATR Budget

The ATR welcomes donations towards the administration and management of the Registry. Donors are provided with a receipt for their donation. 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 from 1 July 2008 – 31 December 2009; their names are listed below.

V. Kennedy
D. Thompson
M. Ovens
B. Kearsley
J. Leece
J. Rees
L. Young
E. Skinner
W. Garside

K. Hansen
I. MacLeod
R. Cambers
G. Cousins
A. Cross
D. Emmett
C. Hughes
J. Murdoch
E. Tyler

The NHMRC Enabling Grant Special Facilities Scheme provides the ATR with a budget of \$500,000 per annum. The funding was successfully extended until 31st July 2014 for 5 more years. In addition, the ATR recovers costs associated with approaching twins for studies from researchers.