




TWINS RESEARCH AUSTRALIA

2019 ANNUAL REPORT

1 January - 31 December 2019






Twin discoveries to benefit everyone's health

THE UNIVERSITY OF MELBOURNE

Melbourne School of Population and Global Health
The University of Melbourne
Level 3, 207 Bouverie Street, Carlton, Victoria 3010
Freecall: 1800 037 021 | Email: info@twins.org.au

www.twins.org.au

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About Twins Research Australia

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

Based at the Melbourne School of Population and Global Health, University of Melbourne, the two main goals of TRA are: (1) to bring twins and researchers together to undertake health research to benefit everyone and (2) to advocate for and engage with twins and multiples.

Our vision

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

Our values

Accountability

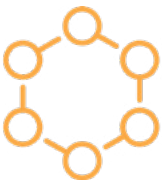
To be accountable to our members, our researchers, our supporters and each other.

Integrity

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

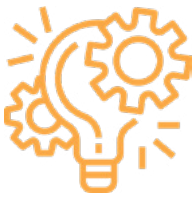
Excellence

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



Collaboration

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



Innovation

To find resourceful and inventive solutions to advance people's health and wellbeing.

Key activity areas

Twins Research Australia activities fall across three key areas: research, knowledge exchange and building research capacity.

1.

Research

a. Conduct research:
lead innovative twin research to accelerate research advances.

b. Cost effectiveness:
leverage cost efficiencies available through the application of the twin design and twin registry access.

c. Enable research:
provide access to participants, de-identified data, expert advice on research methods (twin model design) and twin data analytic services.

d. Registry management:
maintain and build a people bank of over 70,000 twin and family members willing to participate in research.

2.

Knowledge exchange

a. Research community:
translate knowledge in twin research and registry management to the research community through education programs and resources, publications and mentoring.

b. Twin community:
provide evidence-based resources; advocate for their needs to influence policy and practice; and stimulate discussion on the experiences and needs of the twin and multiple-birth community.

c. Wider community:
Communicate study findings back to key stakeholders to influence policy and practice. Raise awareness of the value of research to the wider community.

3.

Building research capacity

a. Education:
teach, train, mentor and support researchers and students in research methods that harness the unique contribution of twins.

b. Collaborative partnerships:
build interdisciplinary collaborations to optimise new knowledge and availability to expertise and research resources nationally and internationally.

2019 highlights

Fast tracking research

A record year for TRA research with over 2000 families and 4000 individuals participating in 9 studies

31 Australian and international institutes involved in our research

Nearly 20,000 invitations sent to twins to participate in our studies

Supporting multiple-birth family health

TRA joins with other leading multiple-birth agencies in an augural workshop to develop national priorities for improved multiple-birth family health

A Global Priority Setting Partnership, including TRA, releases its top 10 multiple-birth global research priorities

Research impact

28 papers published

Reporting on findings in fields such as children's literacy and numeracy, epigenetics, neuroscience and psychology, nutrition, musculoskeletal conditions, eye disease, and twin-specific health issues - see appendix

Expanding twin research capability & capacity

Continuing training and education programs for researchers including the launch of a new Geospatial Workshop

Launch of a first-ever immersive TRA Writing Workshop to undertake and progress writing tasks including research papers

Launch of free series of online training modules for researchers to expand their skills into twin studies

13 travel grants supporting researchers in translating their work

Our lifetime impact

37,000
TWIN PAIRS ON OUR DATABASE

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

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

252
STUDIES

284
RESEARCHERS

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

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

1,228
PUBLICATIONS

Director's message

In 2019, we reinforced the focus of Twins Research Australia as an organisation dedicated to improving the health and wellbeing of all Australians. We are fortunate to have such a dedicated and generous volunteer community of twins and their families who take part in unique research that enables our researchers and collaborators to discover breakthroughs for the benefit of all of us.

TRA's transition to become both an active research organisation, as well as a research-enabling facility, is now complete and we are moving into the next phase of consolidating ourselves as a leader in the fields of public health and health promotion, and exploring new research using large-scale population administrative data linkage.

The year's highlights

We continue to look for funding opportunities to achieve these goals and applied for several grants in 2019, including renewal of our *2015-2019 NHMRC Centre for Research Excellence* funding. As highlighted earlier, we have refined our focus on health for *all of society*, and with the help of our new Chief Investigator team, we hope this application will be very competitive. It takes a lot of time and energy behind the scenes to put together these applications, and we are fortunate to have such a dedicated team at TRA working so hard to achieve our best.

In 2019 we worked, once again, with many expert multidisciplinary teams to conduct and enable ground-breaking research into epigenetics, children's literacy and numeracy, eye disease and musculoskeletal conditions, to name just a few areas. The development and introduction of our innovative geospatial workshops, in collaboration with Dr Callie Little from the University of New England, have been well received. These will be followed up in 2020 with the introduction on our website of a new section that allows researchers to access geospatial information on all of the TRA-registered twins who completed the *Health and Lifestyle Questionnaire*. This data resource will be saved in an electronically secure de-identified format which can be made available to researchers for ethically-approved projects.

We further enhanced our efforts in knowledge translation, with the completion of the Global Twins and Multiples Priority Setting Partnership project. This unique initiative attracted input from more than 1000 multiples, parents, carers, allied health professionals, clinicians and researchers from 31 countries. This highly successful project reflects TRA's ongoing commitment to ensure that the research we conduct or enable is, wherever possible, collaborative, co-designed, participatory and multidisciplinary. The research was published in the prestigious *Ultrasound in Obstetrics & Gynaecology* journal, and will be the subject of a chapter in a 2020 Springer book about *Twin and Higher-Order Pregnancies*, as well as an article in a special edition of the *International Journal of Birth & Parent Education.*

In the Australian context, we conducted our first priority-setting national workshop, on the back of our highly successful Multiple Perspectives report. Both these initiatives were led by TRA's Deputy Director, Kate Murphy, whose drive and passion has always been to shine a spotlight on the issues and challenges of families and health professionals in terms of supporting multiple-birth families to live happy and healthy lives. Kate has returned to her native New Zealand (see further) but, luckily for us, she will continue as an Honorary Deputy Director, helping to guide TRA as we transition into the new millennium.

Team developments

We saw a number of staff changes this year.

The leader of our twin research node at Charles Perkins Centre (CPC), University of Sydney, Susan Carrick: Sue, a twin herself, was instrumental in championing the set-up of the CPC Twin Node. We look forward to expanding this unique collaboration between TRA and CPC under the leadership of our long-time research collaborator, Associate Professor Paulo Ferreira.

TRA Manager, Jenny Boadle: After 15 years, Jenny left in January to take up a key position with the Australian Institute of Family Studies. Sue Malta, a qualitative social science researcher, took up the position of TRA Manager in May.

TRA Research Coordinator and Liaison, Tessa Cutler: Another long-term employee Tessa left in August. She will be undertaking a PhD in 2020 looking at Aboriginal child mental health. Tessa's replacement is Jessica Tyler who has a keen interest in twin research following her Masters of Public Health Project conducted with TRA researchers in 2018.

TRA Research Assistant, Janine Lam: Janine was the project manager responsible for overseeing and delivery of the PSP project which she achieved in record time and with great results. After five years with TRA she took up a research position at Murdoch Children's Research Institute.

As mentioned earlier, Kate Murphy, our Deputy Director of Operations and Strategy left after 10 years to relocate back to New Zealand. Kate may not be in the office every week, however, TRA will continue to benefit from her vast expertise and drive as she continues to act as an Honorary Deputy Director going forward. We also look forward to establishing some highly valued strategic partnerships with our Kiwi neighbours in the very near future!

Vale Grant Townsend 2019: We were greatly saddened to hear of the passing of Professor Grant Townsend in May this year after a long battle with illness. Grant spent a lifetime in the pursuit of dental research and education at the Craniofacial Biology Research Group, University of Adelaide. His insight and commitment to dental research involving twins will be greatly remembered by TRA. Our condolences go to Grant's family and all those who knew him well.

New frontiers

As the last five years have seen, TRA has undergone a period of sustained growth and change – as all good research organisations should do. We focus now on pushing forward into new frontiers of public health initiatives and data linkage.

There is increasing public awareness of the benefits that research involving twins can provide for the greater public good. Much of this awareness is driven by our Media and Communications guru, Lynette Walker, without whom we would not be so well known. In the end, however, our public – and research – face is only as strong as our membership. We are fortunate to have dedicated twins and their families to thank for this – as well as our research collaborators and our wonderful team of dedicated professional staff. We are stronger together – and I personally thank each and every one for their commitment and support of Twins Research Australia.

Warm regards,

Professor John Hopper AM
Director, Twins Research Australia
Director (Research),
Centre for Epidemiology and Biostatistics
Melbourne School of Population and Global Health
The University of Melbourne

TRA Director receives distinguished alumni award

Recipients of the 2019 La Trobe University Distinguished Alumni Award including Professor John Hopper (back row; second from right)

In November 2019, Director of Twins Research Australia, Professor John Hopper AM, was awarded one of La Trobe University's highest honours, a Distinguished Alumni Award. Professor Hopper completed his PhD in Mathematical Statistics at La Trobe and credits his early use of the power of computers for helping him achieve insights otherwise not possible. On receiving the award, Professor Hopper said: *"I realised that I could get the computer to make up for my weakness in mathematical knowledge and be much more clever than me, and quicker."*

Professor Hopper has been an author on more than 1000 papers addressing the genetic and environmental aetiology of diseases and health. In particular he has made seminal contributions to understanding the roles that genetic and environmental factors play on Australia's major cancers and other diseases. He is currently a Redmond Barry Professorial Fellow, and Director (Research) of the Centre for Epidemiology and Biostatistics in the School of Population and Global Health at the University of Melbourne. He is also a National Health and Medical Research Council (NHMRC) Senior Principal Research Fellow. Twins Research Australia is fortunate to have this distinguished academic and researcher as its Director.

Our research

Overview

Twins Research Australia facilitates, conducts and enables research involving twins through our expertise in study design, twin and family recruitment, data analysis and maintaining membership and study data.

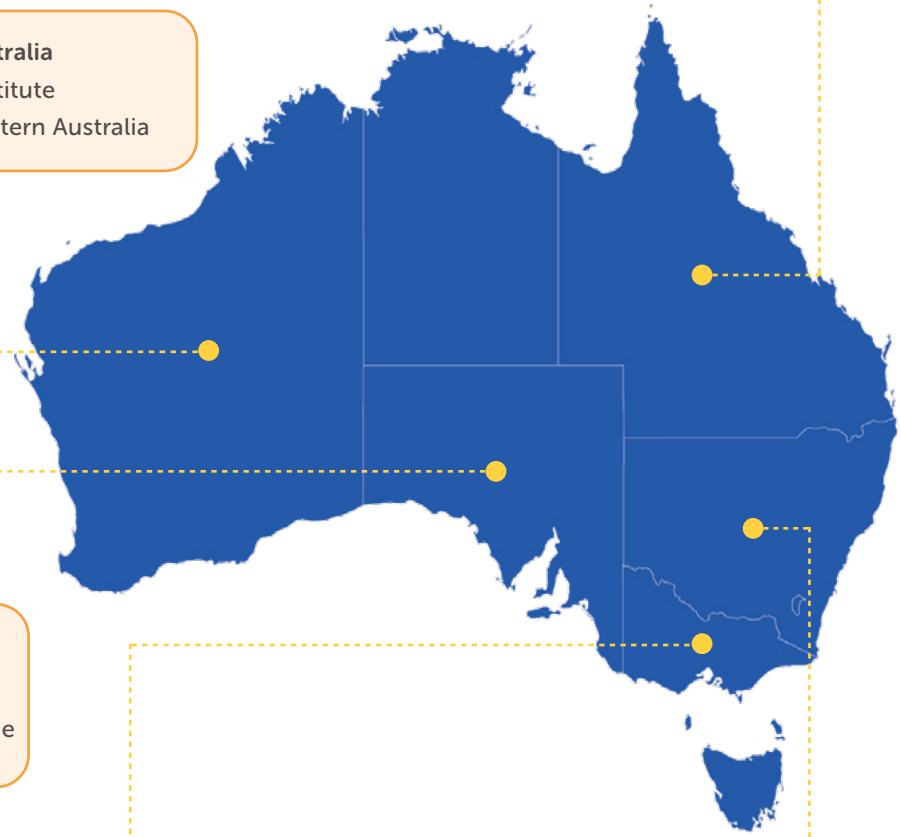
There were 98 active and ongoing studies utilising TRA services and/or involving TRA members in 2019. These studies were undertaken in 26 institutes around Australia as well as five international institutes.

Diagram 1. Location of TRA's active and ongoing studies

International
University of Helsinki, Finland
Aberystwyth University, UK
King's College London, UK
St George's University of London, UK
University of Aberdeen, UK
Stanford University, USA
The University of Southern California, USA
Wellesley College, USA

Queensland
Griffith University
Queensland University of Technology
Royal Brisbane and Women's Hospital
The University of Queensland

Western Australia
Lions Eye Institute
The University of Western Australia



South Australia
Flinders University
The University of Adelaide

Victoria
Austin Health
Australian Catholic University
Deakin University
Epilepsy Research Centre
Monash University
Murdoch Children's Research Institute
Royal Children's Hospital
Royal Women's Hospital
The University of Melbourne

Australian Capital Territory
Australian National University

New South Wales
Charles Perkins Centre
Macquarie University
Sydney Children's Hospital
The University of Sydney
University of New England
University of New South Wales
University of Technology Sydney
UNSW & Neuroscience Research Australia
Victor Chang Cardiac Research Institute

TRA's research work included the active processing of 12 expressions of interests (EOIs) for new research and 10 new research applications throughout the year. There were also nine studies actively recruiting participants and six studies which had de-identified data transferred to them in 2019. TRA also provided ad hoc support to studies in varying stages of development, data collection, data analysis and writing up.

Table 1. Total number of studies supported by TRA/involving TRA members in 2019 by status

Study Status	Number
Application (EOIs, full application, protocol change)	15
Recruiting	9
Recruitment on hold	3
Data collection/data analysis	14
De-identified data analysis	12
Writing up/publishing*	46
Total	98

*includes studies awaiting final follow-up from researchers

Actively recruiting studies

The studies highlighted below were actively recruiting participants through TRA in 2019.

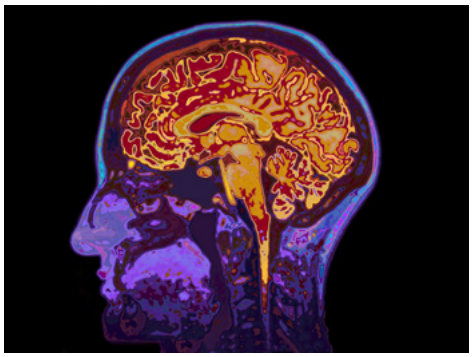
Restless legs syndrome twin and family study

Collaborators: Associate Professor David Champion at Sydney Children's Hospital in collaboration with Dr Tiina Jaaniste and Mr Phillip Aouad

The purpose of this study is to better understand the causes of restless legs syndrome and a similar condition, childhood growing pains. Previous research has identified there are two forms of restless legs syndrome – painful and painless. The painful form is relatively common but, at present, pain is not one of the criteria for diagnosing restless legs syndrome. Through this research, it is hoped to develop more accurate criteria for diagnosis of the condition and to better understand the causes of the two forms.

The researchers are also interested in the relationship between restless legs syndrome and the most prevalent primary (spontaneously occurring) pain disorder of childhood, growing pains. Researchers are investigating if they are variants of the same condition, or whether diagnoses are failing adequately to discriminate between the conditions.

This study recruited one of TRA's largest cohorts of the year, with a total of 1264 twins signing up to take part. TRA also conducted the data collection for this project and received 2291 survey responses from twins and their family members (including children and spouses).



Queensland twin adolescent brain study

Collaborators: Associate Professor Margie Wright at the University of Queensland in collaboration with Professor Greig de Zubicaray and Associate Professor Katie McMahon

The teenage brain is a work in progress, with major changes in the areas that support thinking, reasoning, interpersonal interactions, emotional control and other behaviours. The purpose of this study is to better understand how the brain develops during adolescence and the factors that influence this development.

Recruitment of adolescent twins living in Brisbane and registered with TRA was completed in early 2019. Fifty TRA twin pairs aged 9-12 years have taken part in this study to date.

Investigating the genetic basis of singing ability: a twin study

Collaborators: Professor Sarah Wilson at the University of Melbourne in collaboration with Dr Yi Ting Tan, Trisnasari Fraser and Valerie Yap

Many studies have shown that singing is good for us. By understanding the genetic and environmental influences on singing, the researchers hope to help everyone (twins and non-twins; young and old; singers of all abilities) maximise their singing potential and enjoy more of singing's numerous benefits. Funded by the Australian Research Council, a team of researchers from the University of Melbourne and the University of Montreal are conducting the world's largest twin study on singing ability.

An additional wave of recruitment for this study occurred in February 2019, with 130 new participants taking part.

The resilience study

Collaborators: Dr Justine Gatt at Neuroscience Research Australia and the University of New South Wales in collaboration with Associate Professor Robin Turner, Professor Leanne Williams, Haeme Park, Miranda Chilver, Javad Jamshidi, Arthur Montalto and Rebecca Alexander

This study aims to identify the psychological and brain factors that contribute towards resilience over a 10-year and 12-year follow-up period. It also aims to determine the role of genetics and environment in altering these pathways over time. By studying identical and non-identical twins, it is possible to understand more complex questions about these processes, including the factors that may protect someone from becoming mentally ill, even if they have been exposed to significant stress.

Throughout June 2019, 182 of 268 TRA members who underwent MRI imaging 10 years ago agreed to participate in this follow up phase. Further recruitment of more than 1300 individuals will be conducted in 2020 for the online study component.

Genetic influences on daily physical activity, lower back movement and foot function

Collaborators: Dr Justin Sullivan at the University of Sydney in collaboration with Dr Paulo Ferreira

This study aims to better understand the extent to which genetics influence how we move, and how much we move. This knowledge of the genetic influence on our movement and physical activity is crucial for both prevention and treatment of various diseases including cardiovascular, respiratory and musculoskeletal conditions, as people may be predisposed due to inactivity and abnormal movement.

A small number of pairs were recruited to this study in 2019. Further recruitment is pending funding.

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

Collaborators: Dr Justin Sullivan at the University of Sydney in collaboration with Dr Paulo Ferreira

The purpose of this study is to examine personality, group membership and processes, political attitudes, and health. Specifically, this will be the first study in Australia to take both genes and environment into account to find out:

- Why some people are happiest while in their own company, and shun social gatherings, while others are members of multiple different groups
- Why joining groups can be conducive to mental and physical health
- How political and racial attitudes are co-shaped by genetics and socialization

An additional wave of recruitment for this study occurred in 2019, with 1556 new participants taking part.

Global twins and multiples priority setting partnership

Collaborators: Janine Lam at Twins Research Australia and Professor Asma Khalil at St George's University of London

The aim of this project was to bring twins, higher order multiples, parents, carers, clinicians and scientists together to identify the top priorities for twin and multiple-birth research. In October 2018 TRA released a survey - along with research partners, St George's University and Twins and Multiple Births Association (TAMBA) UK - asking participants from around the world (including TRA members) to nominate up to three important unanswered health research questions for multiple-birth families.

Throughout 2019 TRA analysed the 1120 responses to this first survey to generate a second survey with a list of 89 questions to be ranked in order of most important by participants. TRA released the second survey in May 2019 and received 528 responses which led to the identification of the top 10 unanswered health research questions for multiple-birth families (see appendix for publication).

The health and lifestyle questionnaire

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

The HLQ enables identification of potential participants for specific research studies thus reducing recruitment time and costs for researchers, and unnecessary approaches to ineligible TRA members. It also enhances fast-track research by providing de-identified data to researchers for ethically approved research analyses.

In 2019, invitations for the adult HLQ were sent to 1608 individuals, 238 of whom participated. Invitations for the child HLQ were sent to 547 parents of twin child pairs, 282 of whom participated.

At the end of 2019, a total of 21,297 adult individuals and 12,272 parents of child twin pairs had been invited to participate in the HLQ. Of everyone invited, 7368 adult individuals (including 1974 pairs and 3420 singles), and 4979 parents of child pairs had completed the questionnaire.

Over the course of 2019, five studies utilised data collected from the questionnaire to conduct their research projects. Each study used between 18 to 7107 data records. HLQ data was also used to target study recruitment to appropriate people; to develop educational materials for genetic epidemiology post-graduate level classes and twin statistical methodology workshops; and to provide examples for twin statistical methodology concept papers.

Our research impact

Aboriginal twin birth project

Twins Research Australia has teamed up with the Indigenous Epidemiology and Health Unit at the University of Melbourne to undertake a series of research projects. These will explore pregnancy, birth and early life data on singletons, twins and multiples in Aboriginal and non-Aboriginal populations. In 2019, the initial stages of this collaboration underwent analyses of Western Australia and New South Wales pregnancy and birth hospital records. The aim of these initial analyses was to report and highlight the different birth experiences of multiple and singleton births in Aboriginal and non-Aboriginal populations. The analysis includes novel geocoding methods to gather the distances mothers are travelling to reach hospital and to calculate area-level socioeconomic status. TRA is excited to publish the results of this initial stage and to continue progress on new stages of the project in 2020 and beyond.

Emotional wellbeing

For more than 10 years, Dr Justine Gatt from Neuroscience Research Australia has led a large twin study investigating emotional wellbeing. Many important and novel findings have arisen from her research so far. In 2014, Gatt and her team published a paper concluding that genes and environment have a roughly equal impact on our wellbeing. In 2016, a paper using data from the study supported the idea that clinical symptoms and a person's wellbeing are not necessarily the same thing, and both should be used to fully evaluate someone's mental health. In 2017, it was found that wellbeing was positively associated with various measures of cognitive ability, such as working memory (short-term retention of information for future use) and motor coordination (e.g. finger tapping). Finally, in 2018 Gatt and her team found that a brain structure, called the pons, was associated with levels of wellbeing in individuals. Now, in 2019, recruitment of previous participants began for a 10-year follow-up study. Undoubtedly this will lead to many more exciting findings in the future.

Fatty acid taste perception

Dr Andrew Costanzo of Deakin University led a research team investigating the association between fatty acid taste perception and diet-mediated changes to fat taste receptors. This is an important question as individuals that have impaired fatty acid taste perception tend to consume more fatty foods. The researchers conducted a co-twin randomised controlled trial in which twins within a pair were assigned to either a low-fat or high-fat diet. Changes in fatty acid gene expression were observed as the primary outcome. They found that a certain receptor gene expression (FFAR4) is involved in diet-mediated changes to fatty acid taste perception, and that manipulating it may help in reducing overconsumption of fatty foods.

Education and BMI

Professor Karri Silventoinen of the University of Helsinki and collaborators studied the effects of parental education and genetics on a person's Body Mass Index through a pooled analysis of 29 twin cohorts. It was found that parental education was associated with lower BMI in both males and females, but only after four years of age. Additionally, higher parental education was associated with less variation in BMI due to genetic and environmental factors. Of particular interest for Australian populations, it was found that North American and Australian children had particularly high variation in BMI due to environmental factors associated with low parental education categories. This study developed from a joint project, Collaboration of Development of Anthropometrical measures in Twins (the CODATwins study), which is the largest ever effort to compile information on anthropometric traits in twin cohorts. It includes an Australian cohort of approximately 2660 TRA twins.

Environment and reading ability

In 2019, researchers at Griffith University in Queensland and the University of New England in NSW used data from the International Longitudinal Twin Study (includes 267 TRA twin pairs) to investigate genetic and environmental influences on early childhood reading ability. They found heritability influences were higher at the lower end of reading ability distribution than the higher end of the distribution, and vice versa for shared environment.

Parental reporting of ADHD across countries

In 2019 researchers (MacDonald et al.) from the USA investigated whether there are differences between countries in how attention-deficit/hyperactivity disorder (ADHD) symptoms are perceived. Using a population of 974 twins from Australia and other countries, they explored whether mean ADHD scores differed between countries due to genuine etiological differences, or merely cultural and contextual variation. They found that the differences between countries could not be attributed to actual differences in rates or symptoms of ADHD. Instead, they found that the United States and Australia tended to overreport ADHD symptoms, while Norway and Sweden reported symptoms more accurately.

Multiple-birth research priority setting

Twins Research Australia in collaboration with Twins and Multiple Births Association (TAMBA) UK and St George's University of London investigated globally the top research priorities for twin and multiple births. The project aimed to bring together twins, multiples, parents, carers, clinicians and scientists to identify the top priorities for twin and multiple-birth research. The project conducted two different surveys and received 1648 responses from a variety of stakeholder groups to help gather consensus. The findings of this project concluded the top 10 research questions for twins and multiples to help guide future research to ultimately improve health outcomes of multiple-birth families.

Study invitations

Mail-outs to prospective participants for individual studies are a core component of TRA's daily operations. The scheduling of mail-outs, and the total number of sent approaches, is dependent on the requirements of each research project. During 2019, a total of 19,780 study invitations were sent for nine different studies. TRA also collected data for two different research projects in 2019 and sent a total of 4939 survey invitations to corresponding participants. To preserve membership, TRA limits the number of study invitations per year to each member (where possible). Thus, due to such a busy year of study invitations in 2019, three studies (including TRA's *Men's Health Questionnaire*) were delayed and are currently pending availability of twins in 2020.

Database upgrade

Twins Research Australia's membership database has been undergoing a major revamp in the last couple of years. The previous database had been in place for over 12 years. Built on outdated software, it had limited functionality and support. Developers at Kiandra IT worked with TRA staff and technical specialists at the University of Melbourne to create a new front-end system that was released in October 2018. Ongoing updates to the new database have been a major priority throughout 2019 to allow TRA to more efficiently manage member, researcher and other stakeholder information and processes in the future.

The registry

Twins Research Australia's volunteer members are an integral part of the organisation, and management of the membership is a core component of its function.

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

TRA seeks to keep its members active and engaged by undertaking a wide range of activities. These include: providing opportunities for members to update their details on TRA's website; communicating with eNews and printed newsletter; undertaking phone calls to twins (or their second and third contacts); and following up 'return to sender' mail from study approaches.

TRA 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 overview

Twins and HOMs – including triplets, quadruplets and quintuplets - of all ages, sex combinations and zygosity are eligible to enrol with TRA. In 2019, the database held data on 98,793 individuals, representing 48,720 twin pairs and 469 HOM sets. Of these, 75 percent are adult (18 years of age or older) twins/HOMs, and 25 percent are children (under 18 years of age) twins/HOMs.

Members of TRA are recorded under a specific status, depending on the currency of their contact details and individual preference for involvement in research activities. The current status of individual members of TRA is summarised in Table 2 while the current status of twin pairs of TRA is summarised in Table 3.

Table 2. Registration status of individual twin/HOM members

	Adults	Juniors	Total	Percent
Active	55,666	23,932	79,598	80.57
Questionnaire	990	75	1,065	1.08
Newsletter	508	12	520	0.53
Non-active/current	16,875	735	17,610	18
Total	74,039	24,754	98,793	100

Table 3. Registration status of twin pairs

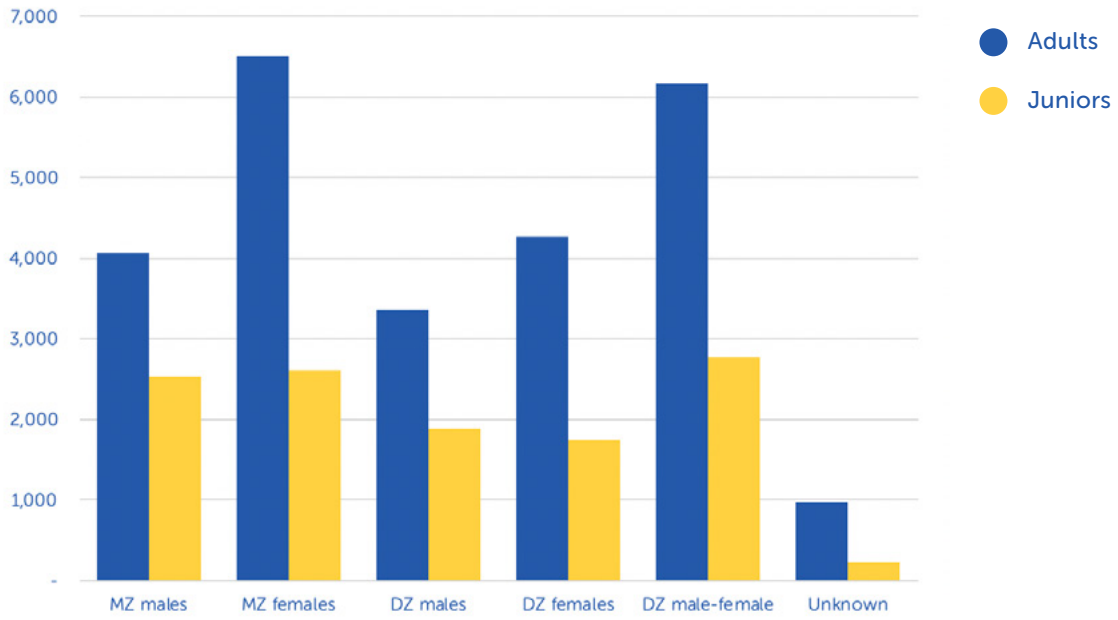
	Adults	Juniors	Total	Percent
Both active/ questionnaire	25,362	11,786	37,148	76.29
One active/ questionnaire	2,520	0	2,520	5.18
Neither active/ questionnaire	8,661	361	9,022	18.53
Total	36,543	12,147	48,690	100

Of the active adult twin individuals, 21,022 have up-to-date email addresses listed with TRA. Of the active junior twin pairs, 10,399 have an up-to-date email address of at least one parent listed with TRA.

Active twin pairs by sex and zygosity

The current numbers of active twin pairs by sex and zygosity are shown in Figure 1. It includes both adult and junior twin pairs where both twins have a registration status of *Active* or *Questionnaire*. Of these twin pairs, 42.3 percent are identical twins, 54.4 percent are fraternal twins and 3.3 percent are of unknown zygosity. Thirty-two percent of these pairs consist of two males, 42 percent of two females and 24 percent of one male and one female.

Figure 1. Active twin pairs by sex and zygosity



Ages of active twin pairs

Parents of twins register themselves and their twin children from birth and members often stay active until the late stages of their lives. Figure 2 and Figure 3 show the distribution of active twin pairs by age groups. Thirty-two percent of active TRA twin pairs are juniors (less than 18 years of age) and 68 percent are 18+ years of age.

Figure 2. Percentage of active twin pairs by age groups

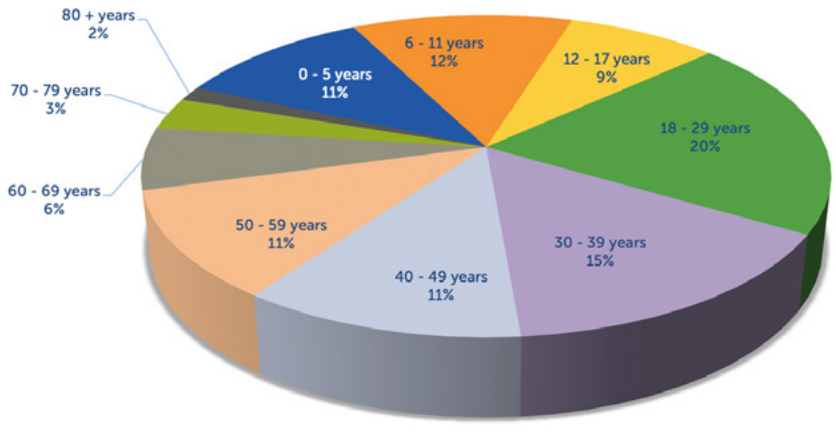
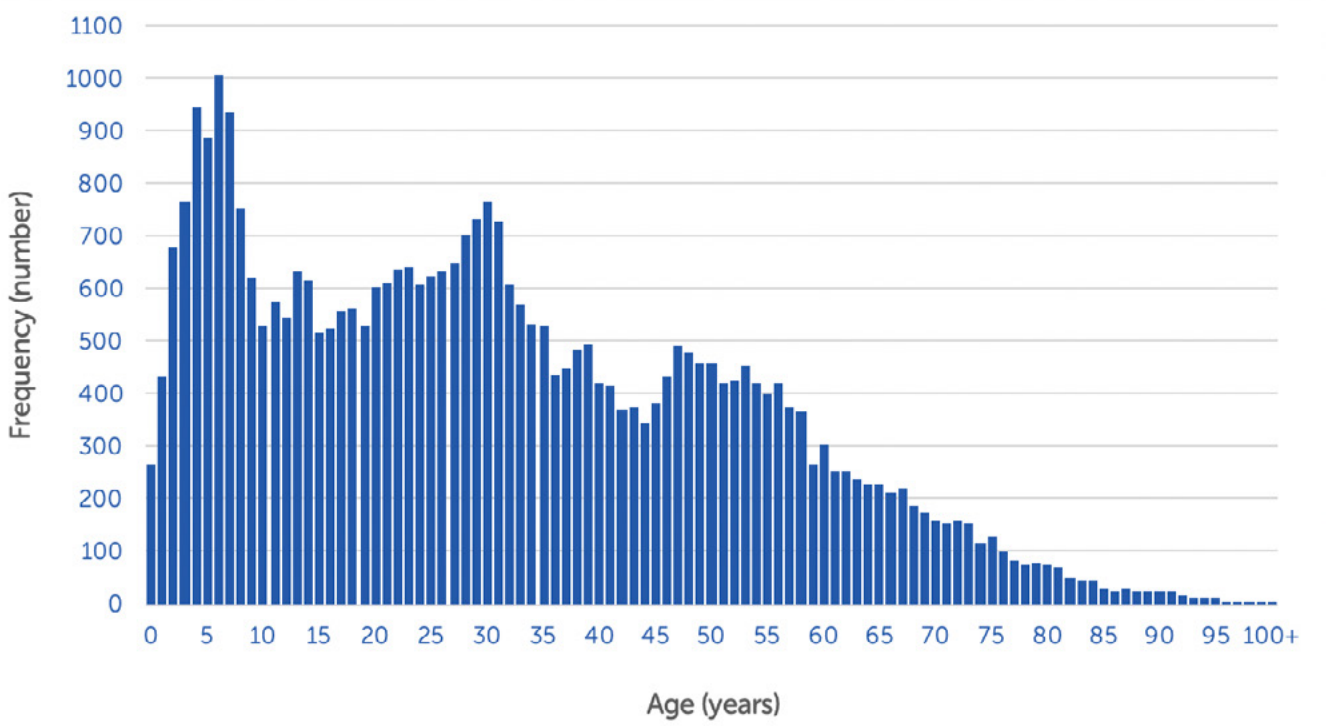


Figure 3. Age distribution of active twin pairs



Distribution of active twin pairs

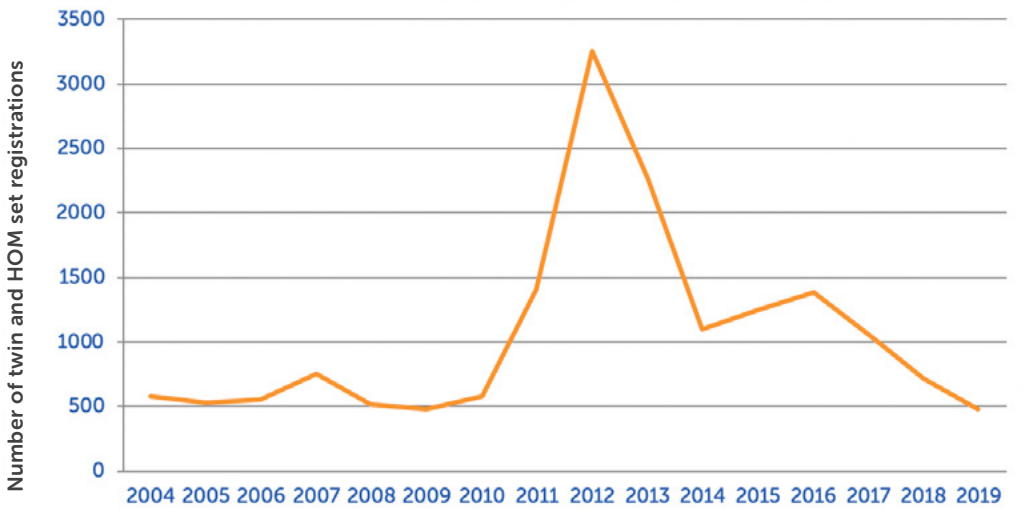
Members reside in all states and territories of Australia. The distribution of active twin pairs by location is shown in Figure 4 together with the overall distribution of the Australian population by state and territory (as reported by the Australian Bureau of Statistics in June 2019). Comparison of the two groups shows that most populated states are also the states where most active TRA members reside.

Figure 4. Percentage of active twin pairs by states and territories compared with the Australian population as reported by the Australian Bureau of Statistics, 2019

New member recruitment

Continuous recruitment of new members is vital to ensure the future viability of TRA. In the reporting period 1 January 2019 to 31 December 2019 TRA recruited a total of 481 twin and HOM sets, 477 of which were twin pairs. The numbers of new registrations by year since 2004 are represented in Figure 5. The 2019 figures show that the number of registrations received are on par with TRA's usual numbers. In 2020 TRA will institute new processes to follow up with adult members aged 18 and above whom we may have lost touch with. In addition, TRA will work in collaboration with GenV – a new Victoria-wide initiative to follow up on all births. These initiatives and others aim to boost TRA's registration numbers in future years.

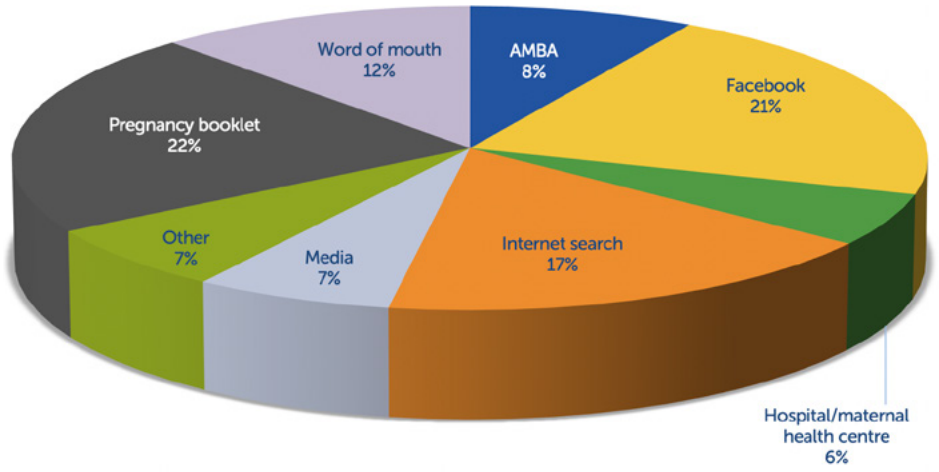
Figure 5. Number of new twin and HOM sets registered with TRA by year since 2004



Sources of recruitment

The TRA *Twin Pregnancy Booklet* and Facebook are the dominant means of registration (22 percent and 21 percent respectively), followed by internet searches (17 percent), word of mouth (12 percent), and the Australian Multiple Birth Association (8 percent). Figure 6 shows each of the main recruitment sources in 2019.

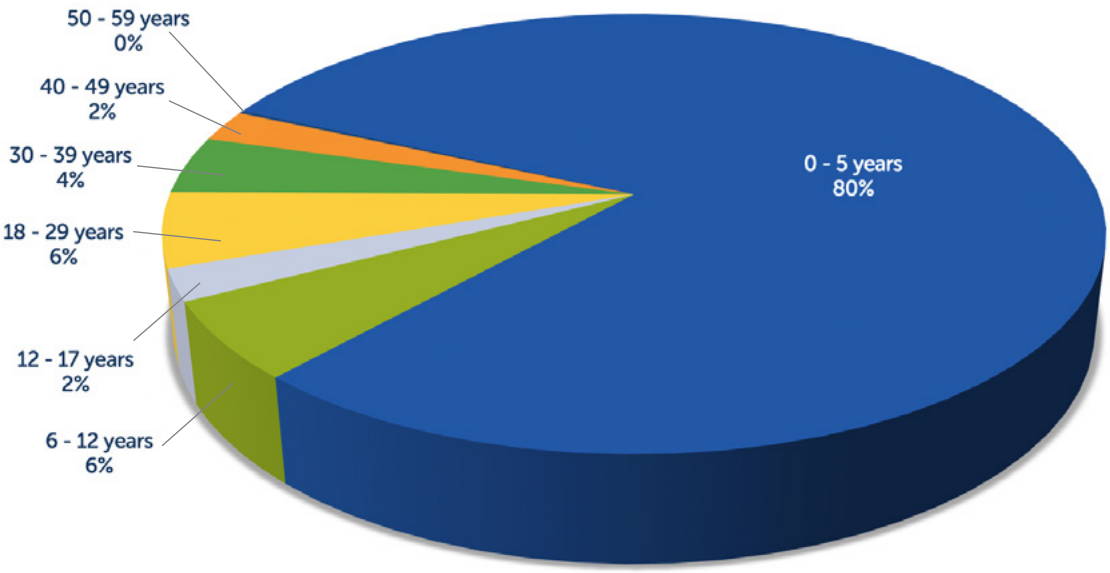
Figure 6. Registration ascertainment 2019: major sources



New member ages

The majority of new members are enrolled with TRA by their parents in the first couple of years after birth. As Figure 7 shows, 80 percent of new enrolments in 2019 were aged 0-5 years. This is consistent with the previous 20 years.

Figure 7. Age break-down of 2019 new member registrations



Updating records

TRA also undertakes proactive tracing of its members. This is an ongoing and important maintenance activity and ensures that the registry remains viable. In 2019 a new strategy to trace previously 'bounced' email addresses was tested which saw 802 email addresses being restored to active members.


Knowledge exchange & engagement

Overview

Twins Research Australia prioritises knowledge exchange and translation in its work to enable twin research to have impact in society. TRA's knowledge translation plan ensures it engages with stakeholders in a structured and systematic way. This plan focuses on the twin community and aims to maximise the transfer of research outcomes to health policy and practice. It aligns TRA with community and funding organisations that expect knowledge translation to be at the forefront of TRA's work.

TRA's knowledge translation programs

Generating a national discussion

This year saw the release in April of a discussion paper, *Multiple Perspectives: What Support Do Multiple-birth Families Need To Live Happy And Healthy Lives?*, a collaboration between TRA, Australian Multiple Birth Association, Twins and Multiple Births Association UK, and International Council of Multiple Birth Organisations.

The paper was a compilation of case studies and opinions collected from TRA collaborators including researchers, health professionals, educators, government agencies, and twin community groups and families.

It provided a wide-ranging overview of issues and challenges for families and health professionals during pregnancy, birth and the early life of twins and multiples. Its aim was to stimulate discussion, identify recommendations, and influence practice and policymaking in Australia to improve health outcomes for multiple-birth families.

The paper identified four high-priority areas for action:

- Create and implement improved multiple-birth-specific educational resources for health professionals
- Support the development of evidence-based research on the financial disadvantage experienced by multiple-birth families; and to enable lobbying of government for funding support
- Advocate for further research to better understand the unique mental health concerns of multiple-birth families
- Advocate for further research to reduce pregnancy and birth complications

Inaugural priority-setting national workshop

Following the release of the paper, TRA hosted an inaugural workshop to bring together all interested parties for a round-table discussion focusing on multiple-birth health. The *National Agenda-setting Workshop: Driving Better Health Outcomes for Multiple-birth Families* was held at the University of Melbourne in December 2019.

The aims of the workshop were to co-design national priorities and next steps in improving multiple-birth family health, and to create a network of passionate people to drive this agenda forward. Workshop participants included health professionals, researchers, educators, government agencies, not-for-profit and community organisations, parents of twins and adult twins. Over 30 participants attended and affirmed their commitment to working together to elevate awareness and action in the four high-priority areas identified by the paper (see above).

The workshop included: background on how and why the paper was developed; presentations from experts on each of the four priority themes; creation of four working groups to develop an action list of next steps and how to take these forward; and identification of potential funding opportunities to implement the next stages of work.

New findings, recommendations and actions presented at the workshop are being collated into a report to be released in 2020. TRA thanks its partners, AMBA and ICOMBO, and all involved in the workshop for their contribution to this vital initiative.

Global knowledge translation initiatives

Since 2018, TRA has been a collaborator in the *Global Twins and Multiple-birth Priority Setting Partnership* in conjunction with Twins and Multiple Births Association UK, and St George's University of London.

The partnership brought together parents, carers, clinicians and scientists to identify the top global priorities for research in twin and multiple-birth health. Its aims were to reduce twin and multiple-birth mortality and morbidity, and to improve long-term

health outcomes of multiple-birth babies and their families. The partnership sprung from concern these issues were not being given sufficient attention globally.

Priority-setting initiatives are potentially powerful and useful, as they guide national and international research funding policies. They also give more validity to research questions by considering the views of parents, carers, clinicians and scientists.

In 2018, the first of two surveys asked for stakeholders' opinions on the unanswered research questions, or 'research uncertainties', they thought were most important. In 2019, a second survey asked stakeholders to rank the research uncertainties they deemed most important.

In October 2019, the collaborators published their findings, outlining the top 10 global research priorities for multiple-birth health (see list of research questions below) and how these priorities were chosen from wide-ranging suggestions across 31 countries.

The findings identified the most pressing issues were in the areas of clinical care for multiple-birth babies and mothers, and psychological health and social supports for parents. This included care during and beyond pregnancy for the short and long-term.

The next step will see researchers and multiple-birth agencies working together – within their specific countries as well as globally – to seek funding for studies in these high-priority areas.

In turn, findings from these studies will guide future directions in multiple-birth education and training, health care and practices, and government support and policies. Ultimately it is hoped these questions can be translated into action to benefit the wellbeing of multiple-birth families around the world, now and for the future.

Twin pregnancy guide

An ongoing popular resource is TRA's *Twin Pregnancy Booklet*. This free printed educational guide (also available as an eBook) is distributed to around 1000 expectant and new parents of twins Australia-wide each year. In 2019, the booklet was revised to reflect the latest evidence-based information and practices from experts in the field, and this new printed version will be available in 2020. As well as its popularity with expectant parents, the booklet is being increasingly used as a resource for hospital prenatal classes and tertiary teaching institutes in nursing.

To expand ways of accessing its twin pregnancy resources, TRA is developing a microsite embedded within the TRA website to deliver online resources. This will enable TRA to provide added information and features in a cost-effective way, and a more flexible, accessible and sustainable delivery channel.

A framework for the microsite was developed in 2019 – with content initially based on the booklet content – and this new channel will be launched in the second half of 2020 to coincide with the release of the booklet update.

General resources

TRA's comprehensive website is central to its communication/translational efforts for members and the broader twin community. New content and website updates were undertaken during the year to improve the user experience.

Other main communication/translational platforms are TRA's social media channels, quarterly eNews, study invites and feedback, and phone-assist service. All twins and parents of twins who participate in studies receive study-specific feedback.

Facebook is TRA's strongest social media channel in terms of followers, reach and engagement – growing by 7.7 percent in 2019 to nearly 14,000 followers. TRA's blog page, *Twins Impact*, is an ongoing popular resource covering issues of interest to members and the broader twin community. The page features stories, opinions and news from researchers, experts, partners, members and staff. Blogs in 2019 covered issues such as: rare types of twin pregnancy; why identical twins can differ in their school progress; and better understanding of restless legs syndrome.

Global top 10 multiple-birth research questions*

- Would staff with specialist training in multiple pregnancies improve outcomes in these pregnancies?
- How can we reduce multiples' admission to the neonatal unit? If admitted, how can we reduce multiples' length of stay in the neonatal unit?
- What interventions prevent and support postnatal mental health problems in parents of multiples?
- How can we prevent maternal complications of multiple pregnancies?
- What are the short- and long-term outcomes in multiple pregnancies? How are these outcomes affected by antenatal events & medical interventions?
- How are higher order multiple pregnancies best managed?
- What are the expected growth patterns of small-for-gestational-age multiples? How can we assess the growth of infant multiples and ensure that they follow a satisfactory growth trajectory?
- What parental interventions can improve the developmental outcomes (ie. speech, language, education) of multiples?
- What are the short- and long-term maternal health risks following a multiple pregnancy?
- What prenatal factors (including changes to lifestyle, health history, personality characteristics etc.) and supports for parents of multiples have the most benefit on birth and ongoing health outcomes for both parents and their children?

**Based on findings from the Global Twins and Multiples Priority Setting Partnership*

Media activity

Twins and twin research continued to generate substantial media coverage and interest throughout the year. This coverage is important to raise awareness in the broader community about the value of twin research to population health. TRA also advocates for multiple-birth families and seeks to raise awareness of the unique lives and special interests of these families.

A highlight during the year was the substantial media interest in the release of TRA's report, *Multiple Perspectives: What Support do Multiple-birth Families Need to Live Happy and Healthy Lives?* This story was shared across the University of Melbourne's media channels globally, including a feature article in its online magazine, *Pursuit*. In particular the story received considerable coverage on radio, with TRA spokespeople undertaking radio interviews around Australia about the unique challenges of multiple pregnancy and birth.

Also creating impact in the media and community was a 2019 TRA-facilitated study with TRA twins into children's dental health at the Murdoch Children's Research Institute. The study found significant environmental influences on dental health in children. The outcomes from this study promise to be of significant impact on the way that oral health is treated in the future.

Other twin-related stories that generated significant media interest Australia-wide during the year were: the challenges of parenting quadruplets and quintuplets (*SBS-TV Insight* special program); and semi-identical twins identified in pregnancy for the first time.

Twin research arguably received the biggest boost in its history when NASA in the USA released the findings of its long-running Twin Study in 2019. NASA conducted an historical study of identical twins where one brother stayed on Earth while the other spent a year orbiting the planet. While researchers primarily investigated what a year in space does to the human body, the study has produced findings that will have ongoing implications for human health, and many fields of health research, for decades to come. The study shone a spotlight globally on the value of twin research, and how it contributes to the health of all humankind.

Building research capacity & capability

Overview

Twins Research Australia works hard to ensure twin research becomes a standard part of the repertoire of population health researchers by promoting a range of capacity- and capability-building initiatives, and by facilitating collaborative research.

TRA is now an established research-active organisation, initiating and conducting projects that utilise its own twin registry and data resources. It also plays a vital role as a research-enabler, openly promoting the registry and associated resources to all researchers, across all disciplines. TRA provides researchers with an established infrastructure and access to a rapidly growing network of twin researchers, statisticians and administrative staff who are experienced in establishing and conducting studies. Further information on resources and access are available at its website.

Research supervision, training and education programs

A key to the increasing success of TRA is its training and upskilling of researchers from many disciplines and of varying skillsets across the country and internationally. TRA's aim is to continually build capacity and capability in twin research through traditional and non-traditional educational training, professional development, and mentoring activities that are integrated with other TRA activities.

Statistical and geospatial workshops

TRA conducts a highly successful workshop series for researchers, *Introduction to Statistical Analysis of Data from Twins*. It focuses on teaching the basics of statistical analysis of data from twins in a straightforward and statistically rigorous way that is accessible to researchers from all disciplines. The program covers exploration, analysis and interpretation of data from twin studies. The focus is on determining when and why particular statistical models and tests are appropriate; the assumptions underlying these; how these can be tested; and what the results of the models mean in the context of specific research questions.

This year also saw the implementation of a new TRA initiative, the launch of its *Geospatial Workshop*, developed in collaboration with University of New England researcher, Dr Callie Little. Geospatial analysis is a highly innovative method which utilises the twins' postal addresses to determine area level socioeconomic status or to calculate distances to public resources, for instance. Such data has the potential to highlight how access to healthcare or other important resources can be affected by geographical location, with consequences for our overall health and wellbeing.

In 2019 TRA held four successful workshops in Sydney and Melbourne (see below). By holding these workshops around Australia, research teams can access hands-on help they wouldn't otherwise receive plus strengthen their relationships within research teams, domains and institutes.

- TRA and the Charles Perkins Centre: 2019 Geospatial Workshop, Charles Perkins Centre, NSW: 4 June 2019
- TRA Seminar and Workshop Program: Introduction to Statistical Analysis of Data from Twins, University of Sydney, NSW: 5-6 June 2019
- TRA and University of Melbourne: 2019 Geospatial Workshop, Melbourne: 16 October 2019
- TRA Seminar and Workshop Program: Introduction to Statistical Analysis of Data from Twins, University of Melbourne: 17-18 October 2019

Twin researcher and statistics group

As part of its national reach and peer-to-peer support, TRA formed a Twin Researcher and Statistics Group in 2018 using the social media platform, Facebook, to enable further teaching and learning from more experienced twin researchers. This group is aimed not only at early career researchers but all researchers new to, or interested in increasing their knowledge of, twin studies. In 2019, researchers and students kept up to date with major global and Australian studies, training and events, and newly published papers and other resources, by subscribing to TRA's free Researcher eNews.

Toolkit for twin research

TRA launched further initiatives as part of its online 'toolkit' or portal, providing comprehensive education and resources for researchers. During 2019, it released further articles under its popular online series, *Conversations in Twin Research*, which aims to showcase the diverse application of the twin method to the research and health professionals' community. Other initiatives included:

- The launch of a free series of online training modules featuring statistical tools and explanations for researchers to expand their skills into twin studies – in their own time and at their own pace. The online modules can be undertaken independently or in conjunction with TRA's hands-on workshops.
- TRA has developed a Sample Size Calculation Guide to help researchers in calculating the sample size required for their classic twin study.

Collaborators in multiple-birth family health: (left to right) TRA Deputy Director, Kate Murphy; AMBA Chair, Ashlee Tenberge; ICOMBO Chair, Monica Rankin; and TRA Deputy Director (Research), Jeff Craig.

TRA writing workshop

This year saw the running of the first TRA Writing Workshop. The workshop ran for five days and included TRA research and professional staff, as well as postdoctoral researchers and postgraduate students. The workshop provided an opportunity to undertake and progress writing tasks in an intensive, fully immersive experience. As well as having the benefits of establishing a 'community of practice' and learning through participation, the workshop helped TRA to achieve a number of publication targets. TRA will continue this practice into 2020 and beyond.

Collaborations and networks

In 2019, TRA built on its existing connections within its networks to capitalise on new opportunities for impactful research. This led to preliminary work with health economists to understand how twins can help us investigate the familial predictors of healthcare use and costs, including those related to a twin or multiple pregnancy.

As a founding member of the International Network of Twin Registries, TRA has continued to play an important role in international collaboration, especially by supporting research teams located overseas that are new to twin research. TRA's PhD graduate, Lucas Ferreira, established a collaboration with Associate Professor Marcos Barreto (UFBA, Brazil) to conduct twin studies on routinely collected health administrative data of Brazilian twins, focusing on predictors of early-life mortality. This work has informed TRA's strategies for conducting twin studies with similar data in Australia.

TRA also continued its partnership with the Brazilian Twin Registry which now has more than 1000 twins registered, the biggest of its kind in South America; and its long-lasting relationships with partners such as the Washington State Twin Registry, the Osaka Twin Registry, the Finnish Twin Cohort and others. These partners play important roles in sharing knowledge that helps TRA to be at the forefront of the science behind twin studies.

Supervision of students by TRA Chief Investigators

Research capacity is also built through TRA-supported scholars and fellows supervising research students as well as providing workshop support for students. The research students are also given training and opportunities in statistical consulting and collaboration (as appropriate depending on skills). In 2019 TRA supervised one Doctor of Medicine (MD), 11 PhD students, three Masters, and two postdoctoral projects.

MD

- Taylor Day, Murdoch Children's Research Institute (supervised by A/Prof Jeff Craig, Prof Mark Umstad, Dr Katrina Scurrah, Shuai Li)

PhD

- Deborah Ashley, Murdoch Children's Research Institute (supervised by Dr Katrina Scurrah and A/Prof Jeff Craig)
- Eloise Cameron, Murdoch Children's Research Institute (supervised by Dr Marc Seal, A/Prof Jeff Craig, Dr Katrina Scurrah)
- Henri Dohnt, University of New England (supervised by Dr William Conventry, Dr Katrina Grasby, Brad Verhulst and Dr Callie Little)
- Lucas Ferreira, University of Melbourne (supervised by Prof John Hopper, A/Prof Jeff Craig, Dr Louisa Flanders)
- Kevin Ho, University of Sydney (supervised by Dr Milena Simic, A/Prof Paulo Ferreira, Ms Marina Pinheiro)
- Sally Larsen, University of New England (supervised by Dr William Conventry, Dr Callie Little, Dr Katrina Grasby and Dr Robert Whannell)
- Channa Marsh, University of Western Australia (supervised by Prof Danny Green, Dr Louise Naylor, Dr Katrina Scurrah)
- Namitha Mohandas, Murdoch Children's Research Institute (supervised by A/Prof Jeff Craig and Dr Kylie Crompton)
- Ana Paula, University of Sydney (supervised by A/Prof Paulo Ferreira, A/Prof Manuela Ferreira, Dr Alison Harmer, Ms Marina Pinheiro)
- Mihiri Silva, Murdoch Children's Research Institute (supervised by A/Prof Nicky Kilpatrick, A/Prof Jeff Craig, Prof David Manton, Dr Katrina Scurrah)
- Hannah Thomas, University of Western Australia (supervised by Prof Danny Green, Dr Louise Naylor, Dr Katrina Scurrah)

MBiostats

- Qiwei Chen, University of Melbourne (supervised by Dr Katrina Scurrah, Dr Enes Makalic)
- Ying Zheng, University of Melbourne (supervised by Dr Gillian Dite, Dr Katrina Scurrah)

MPH

- Sam Crofts, University of Melbourne (supervised by Dr Gillian Dite, Dr Katrina Scurrah)

Postdoc projects

- Alison Gibberd, University of Melbourne (supervised by Dr David Burgner, A/Prof Nicky Kilpatrick, Dr Katrina Scurrah)
- Mihiri Silva, Murdoch Children's Research Institute (supervised by A/Prof Nicky Kilpatrick, A/Prof Jeff Craig, Prof David Manton, Dr Katrina Scurrah)

Travel grants

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

1. Offering financial assistance to Australian researchers to attend TRA workshops and events, thus supporting their training and development in the methodology and practice of studies involving twins.
2. Presenting and promoting TRA-based twin research studies at scientific conferences.

TRA grants 2019

Two travel grant rounds were held in 2019. TRA received an overwhelming number of applications both for travel to national and international research conferences. Grants were awarded to support travel to general research conferences in Brisbane, London, Melbourne and Vancouver; and to the *Twins Research Australia Workshop in Statistical Methodology and Analysis* in Sydney (June) and Melbourne (November).

Travel grants were awarded to a total of 13 recipients, representing nine institutes throughout Australia. Congratulations to the following recipients.

Round 19: general round

- Arthur Montalto, Gatt Resilience Group, Neuroscience Research Australia
- Deborah Ashley, Centre for Epidemiology and Biostatistics, School of Population and Global Health, University of Melbourne (forfeited due to cancellation)
- Haeme Park, Gatt Resilience Group, Neuroscience Research Australia
- Helen McGuire, Discipline of Pathology, University of Sydney
- Janine Lam, Twins Research Australia, School of Population and Global Health, University of Melbourne (forfeited due to cancellation)
- Lingxiao Chen, Faculty of Medicine and Health, University of Sydney
- Mihiri Silva, Murdoch Children's Research Institute, Royal Children's Hospital
- Miranda Chilver, Gatt Resilience Group, Neuroscience Research Australia
- Toby Hughes, Adelaide Dental School, University of Adelaide
- Victoria O'Callaghan, Queensland Brain Institute, University of Queensland
- Yoko Matsuda, Faculty of Graduate School of Nursing Science, Yokohama Soei University, Japan

Round 20: general round

- Claire Galea, Cerebral Palsy Alliance Research Institute, Brain and Mind Research Institute
- Smitha Sukumar, Sydney Dental School, University of Sydney

Personal stories

Deborah Ashtree, Centre for Epidemiology and Biostatistics, Melbourne School of Population and Global Health, University of Melbourne

"I started my PhD in 2018. I was working on the Peri/Postnatal Epigenetic Twins Study (PETS), but I wasn't initially directly involved with Twins Research Australia. My project started out as an investigation into the relationship between early-life exposures (during the first 1000 days) and later-life cardiometabolic health, and this is still a major focus. However, as I began to explore various exposures, I realised there was not much information about recommended or actual maternal gestational weight gain (GWG) for twin pregnancies. As I dug deeper, I uncovered some flaws in the current recommendations, which may mean these recommendations aren't appropriate for all twin pregnancies.

Given the potential implications of GWG for both maternal and twin health, my supervisors, Dr Katrina Scurrah (TRA Biostatistician) and A/Prof Jeff Craig (TRA Deputy Director), put me in contact with others in the TRA team, and I was invited to present at TRA's Multiple Perspectives Workshop.

During this presentation, I discussed some of the results from my analyses, including that more than half of women pregnant with twins in PETS were gaining weight outside the current GWG recommendations; emphasised the limitations of the current GWG recommendations; and introduced ways that we could improve these recommendations to be applicable to more twin pregnancies.

This was followed by quite an in-depth discussion about what's next for this work, and I was able to connect with other researchers involved with TRA. Since 2019, I've been working with TRA researchers, who have been very supportive, and provided many insights into the benefits and challenges of working with twins, families and their data.

Since the presentation, I've been working on exploring the association of maternal GWG during a twin pregnancy with long-term twin health, and I will be presenting these results at the *Nutrition and Growth Conference* in London next year. My aim is to emphasise the importance of comprehensive GWG guidelines; discuss the implications of GWG for twin health; and potentially establish international connections to improve twin GWG recommendations in Australia and internationally. Working with TRA will help achieve these goals, as they are a valuable resource for twin researchers worldwide."

Mihiri Silva, Postdoctoral Research Fellow, Inflammatory Origins, Murdoch Children's Research Institute; and Paediatric Dentist and Senior Lecturer, Melbourne Dental School, University of Melbourne

"I would like to thank TRA for supporting my attendance at *Developmental Origins of Health and Disease* (DoHAD), Melbourne, 2019. Despite the major implications for a person's overall health and wellbeing, oral health is a relatively under-studied field. I authored three posters that were presented at DoHAD: (1) *Dental Service Utilisation in Early Life: Patterns and Barriers Among Australian Children* (2) *Novel Insights Into Epigenetic Differences in Childhood Dental Disease: A Pilot Study*, and (3) *Dental Caries and Body Mass Index (BMI): A Twin Study*. The main findings reported were:

- The findings of this first exploratory, epigenetic study of dental caries and enamel hypo mineralisation have identified several potentially differentially methylated genes at birth associated with disease risk in childhood.

- Although BMI at 18 months of age did not predict dental caries at six years, within and between twin analyses - adjusted for known and unknown confounders - found that within pairs there were advanced dental caries associated with lower BMI at six years.

The funding from TRA enabled me to present and refine my research, so that I can continue my novel work into the determinants and features of oral health by applying various twin analyses, including causal inference.
I was thrilled to find that although my posters were the only presentations at the conference on oral health, they nevertheless attracted considerable interest. I was also able to develop my understanding of how twin studies can be used to understand early life determinants of health and disease. The meeting brought together many leading twin researchers from around the world and gave me valuable insights into using twin studies to understand early life influences on health outcomes."


Our
people

Our people

Twins Research Australia's system of governance ensures accountability, fairness and transparency with all its stakeholders. TRA comprises a leadership team of a director, deputy directors, chief investigators and associate directors from institutes around Australia. We are supported by a team of passionate staff and administered by the University of Melbourne.

TRA is also committed to developing long-term, mutually beneficial partnerships with research, community and corporate organisations that share its goals and values. Our partnerships reflect our local, state and national spheres of influence. Of particular note during 2019 was TRA's collaboration with AMBA and ICOMBO to host an inaugural workshop focusing on developing national priorities and next steps to improve health outcomes for multiple-birth families. TRA also continued its partnership with EasyDNA to provide affordable zygosity testing for our members.

Chief Investigators of the Centre for Research Excellence Grant from the National Health and Medical Research Council

Professor John Hopper, TRA Director, University of Melbourne

Associate Professor Jeffrey Craig, TRA Deputy Director, Deakin University

Professor David Mackey, University of Western Australia

Professor Stephen Simpson, University of Sydney

Professor Brian Byrne, University of New England

Associate Professor Paulo Ferreira, University of Sydney

Ms Susan Carrick, Charles Perkins Centre, University of Sydney

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

Associate Investigators

Professor Elizabeth Sullivan, perinatal/maternal health

Professor Richard Saffery, molecular and cellular biology

Professor Brian Oldenburg, health policy

Professor Margaret Otlowski, health law

Karen Willetts, parent of twins

Professor Mark Umstad, obstetrics and perinatal data

Vince Pollaers, corporate management

Staff

John Hopper, Director

Jeff Craig, Deputy Director of Research

Kate Murphy, Deputy Director of Operations and Strategy; Acting TRA Manager (Feb-April)

Jenny Boadle, TRA Manager (January)

Sue Malta, TRA Manager and Researcher (May-Dec)

Katrina Scurrah, Statistician

Lynette Walker, Marketing Communications Coordinator

Tessa Cutler, Research Liaison and Coordinator (Jan-Nov)

Jess Tyler, Project and Communication Support (Jan-Oct), Research Liaison and Coordinator (Nov-Dec)

Janine Lam, Project Support and Administration (Jan-Aug)

Alison Wright, Project and Administration Support (Feb-Dec)

Jodie Lipman, Member Support and Administration

Lucas Ferreira, Research Assistant

Angela Shi, Graphic Designer

Sue Carrick, Charles Perkins Centre Twin Node (Jan- Sept)

Paulo Ferreira, Charles Perkins Centre Twin Node (Oct-Dec)

Stakeholder satisfaction

The *Annual Researcher Satisfaction* survey is administered each year as part of the *Annual Progress Report* submitted by researchers. This questionnaire provides feedback to Twins Research Australia on their services to twin researchers, and an opportunity to improve on these services where possible.

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

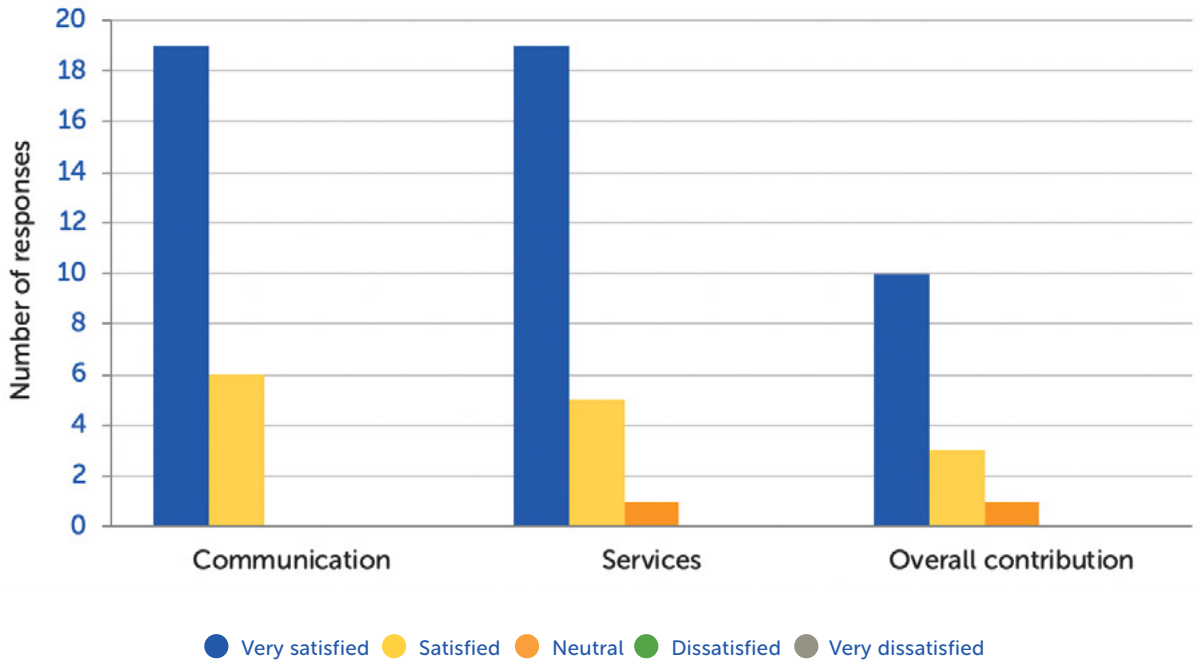
- The researcher's overall satisfaction with communication with TRA
- The researcher's overall satisfaction with the services that TRA provided
- The value of the contribution that TRA made to the overall research project

Responses are recorded as:

1 - Very dissatisfied
2 - Dissatisfied
3 - Neutral
4 - Satisfied
5 - Very satisfied

Twins Research Australia received feedback from 25 research groups for 2019. The communication, services and overall contribution of the organisation were rated very highly. As shown in the figure below, the vast majority of researchers reported being "very satisfied" or "satisfied" across all domains.

Figure 8. Overall satisfaction scores from researchers: Evaluating communication, services and overall contribution provided by the registry



Funding

Funding

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

Generosity of the twin community 2019 annual appeal

Twins Research Australia, like most medical research initiatives, relies on funding sources other than government to continue our vital services and to support the next generation of researchers. TRA's 2019 Annual Appeal resulted in 143 donations from our generous twin community. Money raised was directed towards research and resources to improve health outcomes of multiple-birth families.

Gifts and bequests

Gifts and bequests in a person's Will are ways that TRA supporters can make a real difference to the future health of Australians. If you have any questions or comments, please call 1800 037 021 or email Sue Malta at susan.malta@unimelb.edu.au.

Appendix

Anthropometry

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