

2021 REVIEW

1st January - 31st December 2021



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



Celebrating 40 years of twin research discoveries

Twins Research Australia commemorated its 40th anniversary in 2021, and the year began with the reveal of a [special logo and website home page](#).

Our beginnings

The origins of Twins Research Australia lay in a meeting held in Miami, Florida, in 1973 attended by two Australian researchers.

They learnt of a study with twins looking at the impact of smoking on mortality. Inspired by this research, the two returned home believing an Australian twin registry would provide a vital research tool for medical science here.

Over the coming few years, several state registries were established and, in 1981, they joined forces to establish an Australian Twin Registry.

Based at the University of Melbourne, the new registry's first major initiative was a questionnaire sent to 4,000 twins gathering demographic and general health information. The responses have since formed the basis of many registry-based projects.

1981 to 2021

- This [timeline](#) highlights our major milestones
- Follow the [remarkable achievements](#) of twin researchers across our history in fields such as breast cancer, early life epigenetics, child development, epilepsy, brain ageing, mental health and obesity
- [Explore](#) the evolution of our name and logo: Australian NHMRC Twin Registry (1981-1998), Australian Twin Registry (1999-2016), and Twins Research Australia (since 2017).

Contents

Director's message	2
2021 highlights	2
TwinsFest	3
TRA's research impact	4
Our members	5
Knowledge exchange.....	6
Building research capacity.....	7
Funding	8

DIRECTOR'S MESSAGE

40th celebrations

In 2021, we marked a considerable milestone in the history of Twins Research Australia – our 40th anniversary. To celebrate, we held our first ever online event – a Virtual TwinsFest! This event was a great success, as it allowed our twin members and their families from all around Australia to join in. We were able to extend our heartfelt thanks to them as well as our researchers and partners who have helped TRA across the past four decades.

From our humble beginnings in 1981, we have grown from a small registry to a world-renowned data resource comprising more than 75,000 members and a research-active and research-enabling organisation. That TRA has endured for 40 years is due to our enthusiastic and generous volunteer community, supporters and partners, who continue to be actively involved in distinctive research that enables both ourselves and our researchers to uncover advances of benefit to us all. Congratulations to each and every one.

The year's highlights

The year 2021 saw the continuing impact of COVID-19 on all of us, with Victorians finally emerging from a 6th lockdown after 263 cumulative days. As we did in 2020, the TRA team responded to the months of challenges and sent out a follow-up of our Twins Research Australia COVID-19 Knowledge, Experience, Resilience and Reaction (TRACKERR) survey. It aimed to understand the ongoing impact of COVID-19 on twins and their families. Once again, our members responded strongly, and we had another significant year in terms of research, member support and innovation.

Our NHMRC grant is coming to an end in 2022 and we face further challenges ahead to secure ongoing funding. That said, we continue to seek ways to creatively achieve our goals and ensure our continued operation. Our small and dedicated TRA team spent many long hours identifying and applying for several grants again in 2021, which we hope will be successful.

Future initiatives

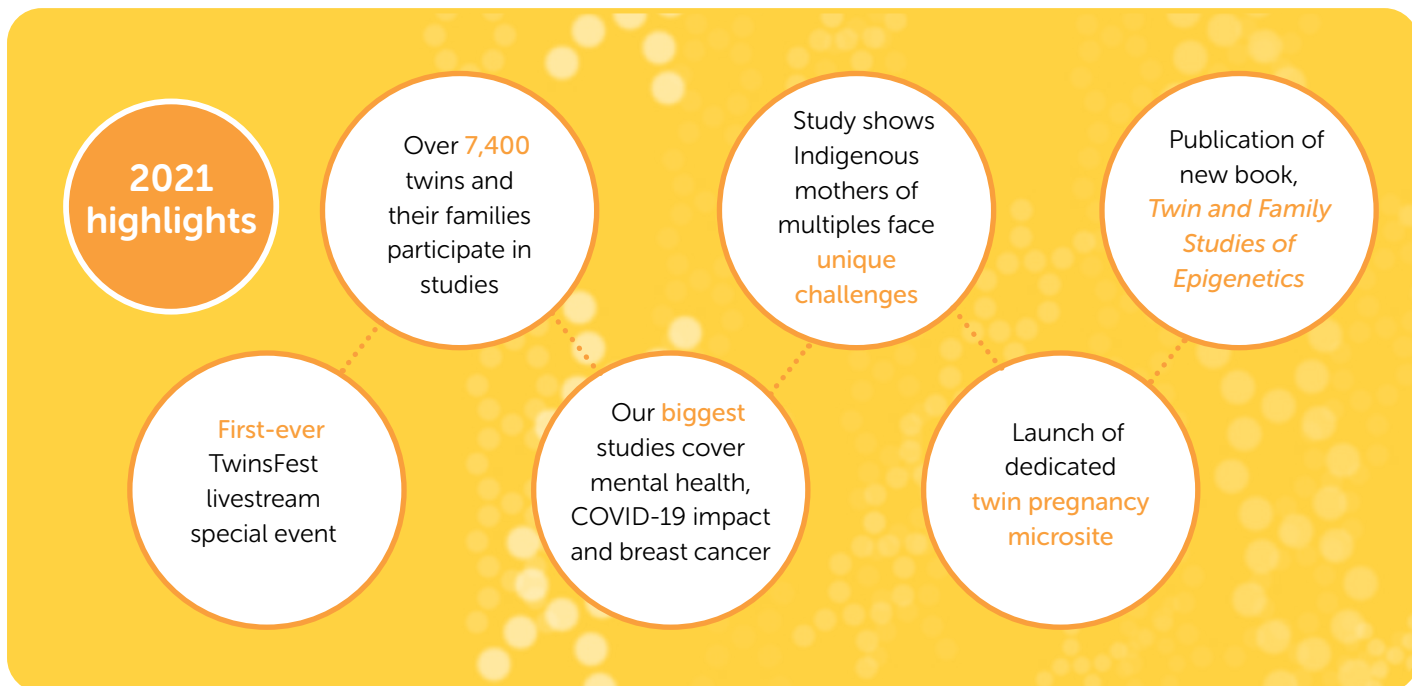
Last year's collaboration with the GenV (Generation Victoria) project continues to develop and we are undertaking preliminary work to establish the first-ever Australian twin birth-cohort nested within a population cohort. As highlighted last year, this could lead to important insights into the relative health and wellbeing of all Australian twins and help us to establish an evidence-base about the needs of twin families.

I would like to personally thank each and every one of our members, their families and friends, and our collaborators, for their ongoing commitment and support of Twins Research Australia. As the COVID-19 pandemic has shown us even more clearly – we are stronger together.

Best wishes



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



AUSTRALIA'S FIRST LIVESTREAM TWINSFEST

Most importantly, we shared our 40th anniversary with the people who made it all possible: our members, researchers and supporters around Australia. This led to TRA producing Australia's first ever livestream [TwinsFest Australia](#) event in November 2021.



Images (from clockwise): twins enjoying the online TwinsFest; singers from Flaxxon; members of Jetty Road band; comedians, the Stevenson Experience.

Over a thousand members and supporters joined in the celebrations – whether by entering a [photo competition](#), buying a raffle ticket, bidding in the silent auction, or livestreaming the show into their lounge rooms.

Twin entertainers and special guests (including comedians, the Stevenson Experience, and bands, Jetty Road and Flaxxon) donated their time and enabled us to raise nearly \$13,000 for multiple-birth health research.



Royal support

One of the highlights of TwinsFest 2021 was the broadcast of a [special recorded message](#) from TRA's International Patron, HRH Crown Princess Mary of Denmark.

As HRH expressed: "There are many health and disease challenges ahead for the world, and I'm pleased to be able to support and encourage this unique area of medical research.... I thank each and every one of you for your incredible contribution.... And I'm very excited about working with you to achieve even more in the years ahead."

RESEARCH IMPACT

TRA's research impact reaches around Australia and the world. We conduct and enable research involving twins through our expertise in study design, twin and family recruitment, data analysis and managing membership and study data.

Studies by the numbers 2021



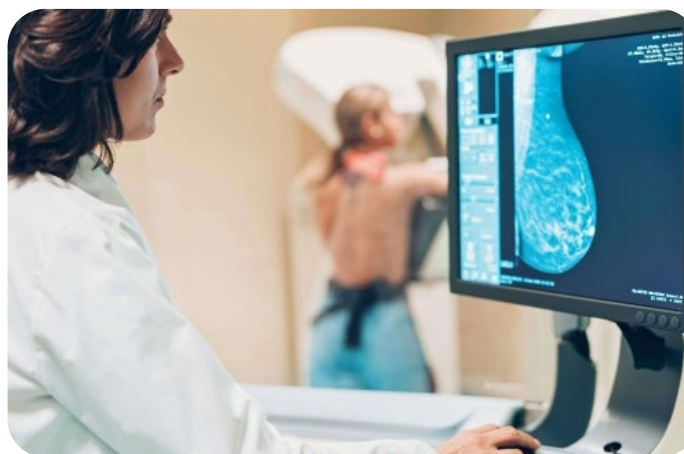
- Six actively recruiting studies: mental health (Monash University), COVID-19 Survey 3 (TRA/University of Melbourne), mammographic density follow-up (TRA/UoM), Junior Health and Lifestyle Questionnaire (TRA/UoM), neurodevelopmental disorders (University of Adelaide), financial decision making (University of Technology Sydney), and International Breast Cancer Study (TRA/UoM)
- 19,697 study invitations sent to members
- 4,686 individuals and 2,741 families participated in studies (78.43% female, 21.57% males)
- Biggest studies:
 - 2,475 participants in the [Resilience and Vulnerability to Mental Health Challenges](#)
 - 2,449 participants in the [Covid-19 Survey 3](#)
 - 78 participants in the [Australian Twins and Sisters Mammographic Density Study Follow-Up](#)
- TRA studies conducted in 26 institutes around Australia as well as 10 international institutes
- View findings from diverse twin studies [here](#)

Unique challenges for Indigenous Australian multiple-birth mothers

Indigenous Australian twins and their mothers face unique challenges, according to [new research](#) supported by Twins Research Australia. The study investigated the birth data of over 64,000 Indigenous twins in NSW and WA.

All mothers of twins face challenges but the study found these may be more difficult to overcome for some Indigenous mothers. Factors included they are: more likely to live far from specialist medical care, younger, more socio-economically disadvantaged, and more likely to have older children. Researchers recommended that specific guidelines for the care of Indigenous mothers and twins may be needed to improve health outcomes.

Twins help to improve breast cancer screening



TRA researchers and twin members have contributed to landmark research into [world-first techniques for predicting breast cancer risk from mammograms](#). These could revolutionise breast screening by allowing it to be tailored to women at minimal extra cost.

The study found two new mammogram-based measures of risk. When these measures are combined, they are more effective in stratifying women in terms of their risk of breast cancer than breast density and all the known genetic risk factors.

Researchers say if successfully adopted, the new measures could substantially improve screening, reduce mortality, mean less stress for women, and lead to more being screened.

OUR MEMBERS

Our volunteer members are an integral part of Twins Research Australia, and member management and engagement are core TRA services.

We manage a database of twins and higher order multiples (HOMs) – or in the case of twins and HOMs under the age of 18, their parents – who have expressed interest in volunteering for health studies.

Twins and HOMs – including triplets, quadruplets and quintuplets – of all ages, sex combinations and zygosity – are eligible to enrol with TRA.

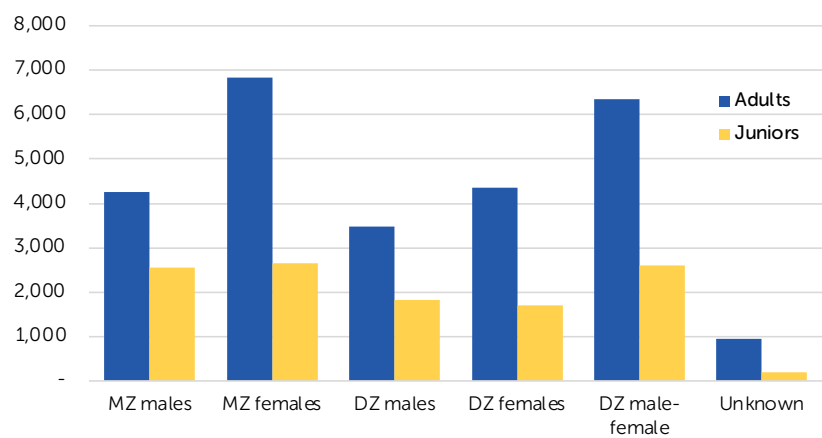
Key takeouts 2021

- 49,727 active twin pairs (or 99,454 individual twins) on our database in 2021
- Of this total, there are 37,858 adult pairs (18-plus years of age) and 11,869 children (under 18 years of age)
- Of those twins, 43% are identical, 54% fraternal and 3% unknown zygosity
- TRA recruited a total of 453 new twin and HOM sets in 2021, 450 of whom were twin pairs

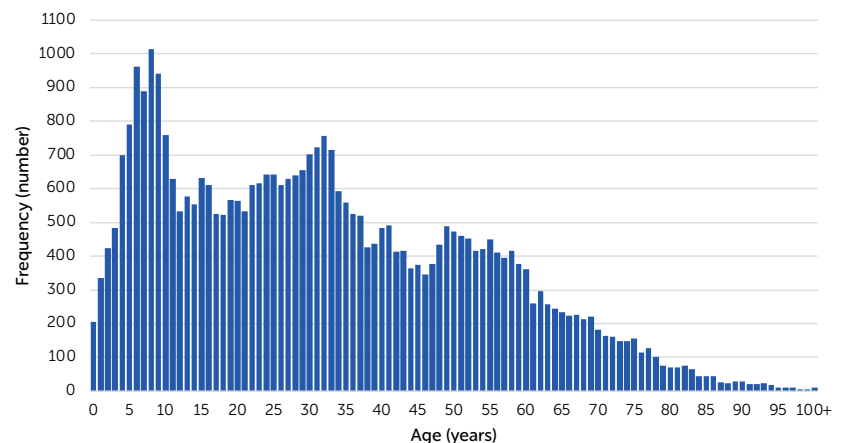
Active twins and HOM members 2021

Set/pair type	Adult pairs/sets	Junior pairs/sets	Total pairs/sets
Twin	37,858	11,869	49,727
HOM	330	150	480
Total	38,188	12,019	50,207

Active twin pairs by sex and zygosity



Age distribution of active twin pairs



KNOWLEDGE EXCHANGE

Twins Research Australia prioritises knowledge exchange and translation in its work to enable twin research to have impact in society. We aim to maximise the transfer of twin research outcomes to broader health policy and practice.

As part of this work, TRA continues its close partnership with the twin community, especially the [Australian Multiple Birth Association](#) and [International Council of Multiple Birth Organisations](#), to support research and resources to address health issues of particular concern to them.

Launch of twin pregnancy digital resources



Since 2010, TRA has distributed a popular printed *Twin Pregnancy Booklet* to around 1,000 expecting and new parents of twins annually. As a special initiative in our 40th anniversary year, TRA launched a new way of accessing these resources: a dedicated microsite, [Twin Pregnancy and Parenthood](#).

The microsite provides expanded features and resources, and a cost-effective, flexible and sustainable mode of delivery. Developed by TRA, in conjunction with health professionals and multiple-birth parents, it contains free evidence-based information about twin pregnancy, birth and early parenting. An updated version of the booklet is also available as a free downloadable eBook.

Increasing awareness

Other activities undertaken by TRA to increase awareness of twin research and its contribution to public health:

- Updating and uploading new content to its central communication platform www.twins.org.au
- Continuing diverse communications to reach as broad an audience as possible (e.g. [Facebook](#), [Member eNews](#), [Researcher eNews](#), study invites and feedback, and phone-assist service)
- Media campaigns to raise public and twin awareness. Issues that gained widespread attention in 2021 included:
 - [New discoveries into the origins of identical twins](#)
 - [Twins contribute to world-first mammographic measures](#)
 - [COVID-19 and twins: huge impact of lockdown separation](#)
 - [Why parents of twins should test for zygosity](#)
 - [Twins and the biological ageing process](#)
 - [Five things research from twins teach us about health, behaviour and what makes us unique](#)

BUILDING RESEARCH CAPACITY AND CAPABILITY

TRA conducts its own research as well as enabling twin research across Australia and the world. It openly promotes the twin 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 our [website](#).

Research supervision, training and education

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. In 2021, TRA continued to build capacity and capability in twin research through the following educational training, professional development, and mentoring activities:

- Since 2020, TRA has completed three phases of an adult version of the TRACKERR (Twins Research Australia COVID-19 Knowledge, Experience, Reaction, and Resilience) study, and a first phase for parents of twins and triplets. De-identified data from these surveys has been made [available](#) for use by external researchers and students for ethically approved projects
- TRA researchers attended and presented papers at the 19th International Congress on Twin Studies held in-person and online in Budapest on the 11th-14th November
- TRA continues to build international collaborations with institutes such as the [International Network of Twin Registries](#), [national twin registries](#), and [International Council of Multiple Birth Organisations](#)
- We offer [workshops](#) and [online training modules](#) for researchers to expand their skills into twin studies
- Research capacity is also built through TRA-supported scholars and fellows supervising research students as well as providing workshop support for students. There were 19 PhD, 11 postdoctoral, 11 Master and one Honour students who received support during 2021.

Release of new book, *Twin and Family Studies of Epigenetics*

TRA Director, Professor John Hopper, and researcher Dr Shuai Li have edited a new volume in the series, *Translational Epigenetics: Twin and Family Studies of Epigenetics*.

Together they have gathered expert opinions from more than 15 leaders in the fields of epigenetic twin and family study research methods, recent findings across various disease areas, and future directions for research and clinical application.

TRA researcher receives lifetime achievement award



TRA Deputy Director, Professor Jeff Craig, has received the ISTS* James Shields Award for lifetime contributions to twin research. A researcher at Victoria's Deakin University, Professor Craig studies the role of epigenetics in mediating the effects of early life environment on the risk for chronic disease.

He has established many longitudinal cohorts, most involving twins. He is a Chief Investigator on the NHMRC-funded TRA Centre of Research Excellence and President of the International Society for Twin Studies. He also leads the interdisciplinary Gen(e)quality network which focuses on the ethical, legal and social issues of genomic testing.

* *International Society of Twin Studies*

ONGOING FUNDING

Twins Research Australia is funded by a Centre of Research Excellence Grant (2015-2022) 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.



Community donations

However, like most medical research entities, we rely on funding sources other than government to continue our vital services and to support the next generation of researchers. We thank those who supported our first-ever 40th Anniversary Virtual TwinsFest this year that raised funds for research and resources to support multiple-birth families. We welcome further donations to our research [here](#).

TRA also continued its partnership with EasyDNA, which provides a discounted price for [zygosity testing](#) especially for TRA members. EasyDNA makes a small donation to TRA for each DNA test purchased by a member.

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 email Sue Malta at susan.malta@unimelb.edu.au