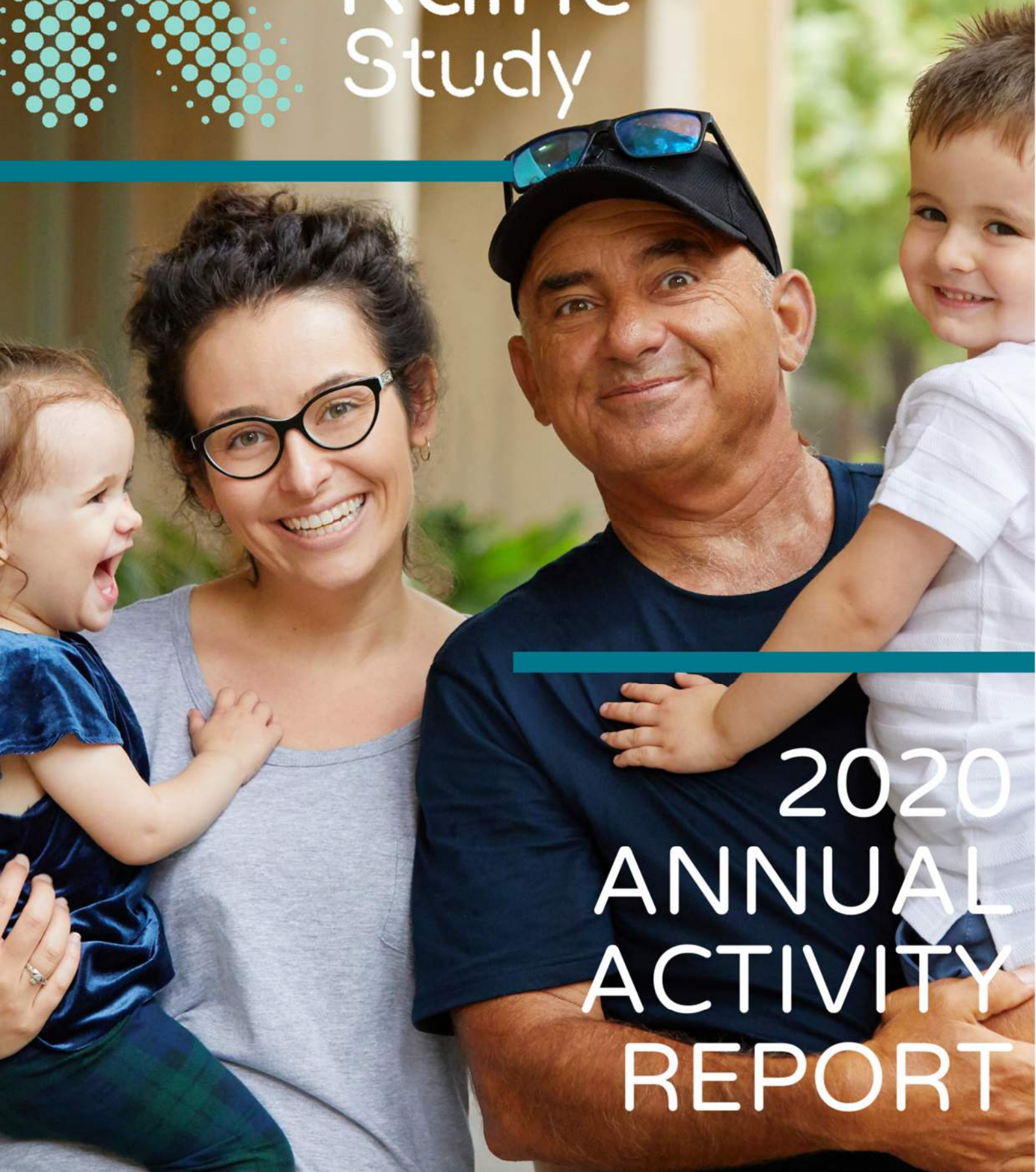




the Raine Study



2020 ANNUAL ACTIVITY REPORT



3 Life changing years





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The Western Australian Pregnancy Cohort (Raine) Study 1989 Staff Photo



Original Staff Reunion 2020





Message from Our Chair

2020, a landmark year. 2020 was many things to many people. While it was a year of change and discomfort, it was also a time for resilience and new definitions of success. Across all aspects of the Raine Study, 2020 was a year in which our abilities as an organisation were tested, but one from which we ultimately emerged stronger than before. Our commitment to collaboration, curiosity and the enablement of life-changing research shone through in ways none of us may have expected at the start of the year, but which all of us could be proud of by year end.

It was a year of change that none of us could have imagined. Firstly, the COVID-19 pandemic brought about a physical shutdown of the University of Western Australia's (UWA) campus on which the Raine Study is located. Despite significant infrastructure challenges, staff remained productive and connected with their co-workers while working from their homes. Operations Manager Aggie Bouckley is to be commended for her tireless work in partnership with our UWA hosts for making this happen.

The impact of COVID-19 also forced the postponement and then cancellation of the major event we had planned to celebrate our 30-year anniversary. While we were disappointed that we could not hold the event as desired, it provided us with the opportunity to imagine new ways to celebrate in ways that we hope will even more meaningful to all our Raine Study community regardless of age or location. A notable example of this new low-key but impactful approach to celebrations was the morning tea in honour of the original staff of the Raine Study held in December. It was a very moving experience to hear their memories of the very early days of the Raine Study from back in 1989. None of them could have imagined the incredible results achieved over the last 30 years when they first started collecting information from the wonderful women who agreed to be part of the study.

More than 30 people were able to attend the morning tea and help us recreate one of the earliest photos of the Raine Study team. At the event, Raine Study founding investigator Professor John Newnham thanked all those present for the hard work, commitment, and vision (see pictures, opposite page.)

Continuing with the theme of change, 2020 saw us bid farewell to Professor Peter Eastwood at the conclusion of his 8-year tenure as Director of the Raine Study. We are deeply grateful for his many achievements at the helm of the Raine Study since 2013, working in close partnership with outgoing Scientific Director Professor Leon Straker to establish the systems needed to support a research enterprise the size of the Raine Study.

Major accomplishments included direction of the Gen2-22, Gen1-26, Gen2-27 and Gen2-28 year follow-ups; ongoing strengthening of Raine Study's scientific reputation across the world resulting in the milestone publication of 500 research articles using data from the Raine Study; and of course their own individual and collaborative contributions to 30 years of world-leading life-changing research and discovery. As well those scientific achievements, Professor Eastwood led the transition of the Raine Study from the Telethon Kids Institute to the present new headquarters at UWA, the establishment of the Raine Study as an unincorporated joint venture with all five West Australian Universities represented on the board, along with the Telethon Kids Institute and the Women and Infants Research Foundation with an independent Chair. It has been my privilege to hold this position for the past three years.

While Peter and Leon will both be missed, with change came the opportunity for new development. Professor Anne Smith succeeded Professor Leon Straker as Scientific Director, though she departed this role at the end of June. In the absence of a Scientific Director for the second half of the year, Scientific Manager Dr Juliana Zabatiero took on many of these responsibilities in addition to fulfilling her own role, culminating in the excellent showcase of Raine Study scientific impact at the 2020 Annual Scientific



Meeting. Redesigned and delivered as a virtual event for the first time, we hosted over 90 attendees and heard presentations from 16 early career researchers from across our academic community.

In November 2020 we welcomed Professor Romola Bucks (UWA) as our new Director. While she did not officially commence until the start of 2021, in just a few short months she has already made her mark on the Raine Study with the recruitment and appointment of Associate Professor Rebecca (Bec) Glauert as our new Scientific Director. Bec is the Head of the Developmental Pathways and Social Policy Team at Telethon Kids Institute and an internationally recognised expert in data linkage. Her expertise will be utilised well as we seek to identify and grow new opportunities for the use of our data nationally and internationally. Related to this, we have started meeting regularly with two other WA-based cohort studies, the ORIGINS Project and the Busselton Health Study which runs the longitudinal Busselton Healthy Ageing Study to explore the potential for collaboration.

Romola has also demonstrated great efficiency in the speed with which she has familiarised herself with the Raine Study's staff, organisational structure and UJV partners, including the organisation of the core team's first ever planning and team development day in February. We are fortunate to have experienced such a smooth transition between the outgoing and incoming Directors.

Still on the theme of change, I want to thank and acknowledge the contributions of outgoing members of the Board of the UJV, in particular Charlotte Diaz, Generation 2 (Gen2) participant representative who is now the proud mother of one of the next generation of participants in the Raine Study, Professor Margaret Jones (Edith Cowan University/ECU) and Professor Greg Blatch (The University of Notre Dame Australia/UND). We welcomed new Board members William Aitken (Gen2 participant), Associate Professor Therese O'Sullivan (ECU) and Professor Gervase Chaney (UND) in their place.

In conclusion, I would like to thank all of the Board members of the UJV for their contribution to the governance of the study, the Directors (past and present – Professor Peter Eastwood, Professor Leon Straker, Professor Anne Smith, Professor Romola Bucks and Associate Professor Rebecca Glauert) for their ongoing leadership, Operations Manager Aggie Bouckley, Heather Campbell who provides invaluable support to the UJV Board, and the entire team of the Raine Study for their dedication and hard work in the past year of challenges.

Most of all, I thank our four generations of participants. While our milestone celebrations may not have gone to plan, we hope they know how very grateful we are for their decision to stay involved with the Raine Study as, without them, there is no Raine Study. We look forward to showing them our appreciation by continuing to strive for excellence for all that we do, and achieving many new successes as we enter our fourth decade of life-changing discovery.

Jan Stewart

PSM, BA, MSW. HonDLitt.WAust, FAIM, GAICD
Chair, The Raine Study
April 2021





Executive Summary

As it was for so many other organisations in Australia and around the world, 2020 was the year of change: change from what was planned; change in staffing. Despite the challenges of COVID-19, of working from home, and the departure of long-serving staff members and new staff arriving, 2020 was a successful year for the Raine Study.

Response to COVID-19

The Raine Study team responded with their usual resilience and professionalism to the University shutdown that saw our staff working from home between March and July 2020. Few staff had the computer facilities to work from home, so setting that up (remotely) took considerable time. We are enormously grateful to the UWA IT service which supported us through COVID-19 and has continued to provide us with support during 2020.

Progress Against Strategic Plan

1. Build Organisational Capacity

Responded to senior leadership changes

- The biggest challenge in 2020 was the change of senior leadership. Late in 2019, Professor Leon Straker, Scientific Director, moved to the role of Scientific Advisor. That role ended in June 2020.
- Professor Anne Smith took on the role of Scientific Director, a role she held from January to June 2020.
- Dr Juliana Zabatiero, our Scientific Officer, stepped up to the role of Scientific Manager in January 2020 and covered some of the Scientific Director portfolio from June: a job she did very ably.
- Professor Peter Eastwood indicated his intention to step down from his role as the Raine Study Director.
- Peter implemented the first step in our leadership succession plan, recruiting Professor Romola Bucks to the role of Director. Romola joined the Raine Study in November 2020 for a handover period until Peter's last day on 18 December 2020.
- As part of step 2 of the succession plan, we advertised for a new Scientific Director and interviewed for the position in December 2020.
- We celebrated Peter's Directorship at a farewell event on 11 December 2020.

Strengthened the UJV partnership:

- Encouraged continued high-level partner support and good governance of the Raine Study by the members of the Board of the UJV.
- Provided continuing validation of the value of partner investment and involvement.

Strengthened staff capacity

- Provided professional development opportunities to staff.
- Recruited highly skilled professionals into vacant positions including Communications Manager, Data Officers, Director, and Information Technology (IT) Business Partner.

Strengthened committee functioning

- Revised Terms of Reference for Scientific Management Committee and Scientific Review Committee, including processes for management of perceived and real conflicts of interest.
- Developed membership and roles of Management, Scientific and Participation Committees.



- Facilitated regular and consistent meetings of Committees - Scientific Management Committee (22) meetings, Operations Management Committee (11) meetings, Scientific Review Committee face-to-face (3) and electronic (8) meetings, and Community Advisory Committee (4) meetings.

Strengthened participant engagement

- Distributed three newsletters (February, June, November) to Gen1 and Gen2 participants.
- Used social media platforms, video conferencing tools, newsletters and content on our website and engagement to help raise participant awareness of the real-life value that is gained from their historical and ongoing participation in the Raine Study.
- Continued participant engagement meetings during COVID-19. Four meetings were held via teleconference resulting in higher than usual attendance.

Maintained adequate facilities

- Worked with UWA to repair the photocopy room roof following flood damage.
- Proactively coordinated work from home computer and laptop access during the COVID-19 shutdown.

Built IT capacity

- Finalised development of the Raine (Study) Online Submission System (ROSS) version 2.0, funded by the Western Australian Health Translation Network (WAHTN).
- Engaged ISA Technologies to progress the continued support and development of ROSSv2.0.
- Recruited Ray Smith in June 2020 to assist the Raine Study in building IT and data management capabilities.

2. Create financial sustainability

- Maintained institutional partner contributions.
- Explored opportunities for industry-funded use of the data within ethical and legal standards, establishing that aggregate/group level data can be shared under approved projects with industry-funders.
- Facilitated grant applications to local, national and international grant schemes. 11 grant applications were submitted in 2020, of which 2 were successful and we are awaiting the outcome on 3 (as of April 2021).

3. Build science capacity and culture

Increased participant engagement in science

- Reviewed the success of embedding participants in Special Interest Groups (SIGs). Identified key learnings from this trial to be implemented in the future.
- Completed 2x online Researcher Information sessions (webinars) targeting participants and featuring highlights from the Mental Health and Physical Activity SIGs, to remind participants of the impact of their ongoing involvement in the Raine Study, as well as provide them with opportunities to engage with different researchers from across the SIGs as well as our UJV partners.
- Sought feedback from participants following these webinars, identified key learnings to apply to future engagement activities.

Developed Special Interest Groups

- Researchers from the Raine Study SIGs worked with participants to develop posters sharing successes from the Raine Study as part of the 30-year celebrations.

Developed resources

- Completed harmonised quality control on six historical data sets with Lotterywest support and commenced quality control of another three historical data sets.



- Commenced quality control on three recently completed follow-ups.
- Received overarching Human Ethics Research Committee UWA approval for ongoing use of all historical data.
- Prepared Standard Operating Procedures for core data collection methods and curation processes.
- Data collection on Gen2-28 follow-up completed by Saturday 21 March 2020 (only minor impact by COVID-19).

Increased science activity

New forms submitted in ROSS included:

- 69 new projects
- 125 new data access requests
- 4 new biosamples requests
- 85 new manuscript proposals
- 65 new manuscript submission
- 462 new amendments to projects and related forms
- 49 published papers in peer-reviewed journals in 2020, resulting in a total of 599 published papers using the Raine Study data since the start of the Raine Study.

4. Enhance awareness and impact

- Despite the impact of COVID-19, which dominated media for the majority of 2020 and resulted in needing to pause plans to promote the Raine Study's 30th anniversary, the team secured several pieces of media coverage which included online as well as traditional and newspaper stories.
- Researched and developed 8x news stories for the Raine Study website on the following topics:
 - 2020 Senior Australian of the Year, Professor John Newnham (January)
 - New Scientific Director of the Raine Study, Professor Anne Smith (January)
 - The Raine Study 2020 Top Up Scholarship Winners (May)
 - New Institutional Partner, the University of Newcastle (May)
 - 2020 Annual Scientific Meeting (October – multiple stories)
 - New Director of the Raine Study, Professor Romola Bucks (November)
 - The Raine Study Wins UWA Green Impact Award (December)
- Produced two online Researcher Information sessions (webinars): 'Pregnancy to Present Day: 30 Years of Mental Health Research in the Raine Study' (August), and 'Let's get physical, the importance of physical activity' (September).
- Held the Raine Study's first virtual/blended Annual Scientific Meeting (74 external attendees, 11 presenters registered, 9 Raine Study staff, total of 94 attendees logged in).
- Hosted a 30th anniversary morning tea to celebrate the legacy of the original Raine Study team. We welcomed more than 30 original staff members along with family and friends, with founding investigator Professor John Newnham as guest of honour.

Activities Planned for 2021

Ongoing celebration of the 30th Anniversary of the Raine Study

- The celebration of the 30th anniversary of the Raine Study began in November 2019 at the Annual Scientific Meeting, which highlighted the exceptional value of 30 years of high-quality data.
- A major community event was planned for 2020 but was first postponed and then cancelled given continuing uncertainties around COVID-19.
- Moving forward, we have revised our plans and will work with participants, researchers, and other key stakeholders to celebrate via a series of activities utilising digital platforms, video, and social media. By removing the event element of our celebrations, we believe that we can still celebrate this incredible milestone in ways that will be just as impactful and even more meaningful to all our Raine



Study participants, researchers, community, family, and friends. It also provides us the opportunity to plan activities in which everyone can participate, not just those based in Perth.

Ongoing organisational development

- Developing more secure financial basis for ongoing collection of core data.
- Submit application for funding for WA Cohorts Data Portal with ORIGINS Project, Busselton Health Study and Telethon Kids Institute.
- A webinar and linked workshop sharing the Raine Study with early and mid-career researcher academics from all WA universities and relevant research institutes.
- Information events with researchers/health organisations to promote the work of the Raine Study.
- Streamlining administrative processes to reduce the burden on Raine Study researchers and Raine Study staff and increase efficiency.

Ongoing data collection

- Collection of Gen2-28 year follow-up Echocardiogram data.
- Planning for a possible future follow-up of Gen1 and Gen2 (pending funding).

We are enormously grateful to our participants, our researchers, and our funders, particularly the University of Western Australia, the Raine Medical Research Foundation and the National Health and Medical Research Council (NHMRC), for their continued support of the Raine Study. We look forward to working with you all in 2021 and beyond.

Professor Romola Bucks
Director, The Raine Study



Associate Professor Rebecca Glauert
Scientific Director, The Raine Study





About The Raine Study

Our vision

Advancing knowledge, enhancing lives.

Our mission

To improve lifelong health and quality of life through ground-breaking, impactful research that examines influences, pathways and outcomes from before birth and throughout life's course.

Our motivation

We are committed to innovation, discovery, and scientific rigour. Our staff, researchers and participants do what they do for the greater good.

We strive to provide a scientific environment that is flexible, respectful, and collaborative to our participants, researchers, and all those we work with.

We search for new discoveries that can improve human health and quality of life.

We are constantly building new knowledge that changes people's lives.

“In Australia and across the globe, the Raine Study is a unique resource which stands out from most other studies in the world.”

Who we are

The Raine Study is Australia's longest-running public health study, and one of the most extensive multi-generational cohort studies of pregnancy, childhood, adolescence and adulthood anywhere in the world. The Raine Study is currently celebrating the extraordinary milestone of 30 years of world-class, life-changing research.

Established in Perth in 1989 with funding from the Raine Medical Research Foundation, the Raine Study was the first of its kind to track participants from before they were born, to determine the role that early life events (from the womb onwards) would have on later life.

A total of 2,900 pregnant women were recruited by the Raine Study between 1989 and 1991 (Gen1), and 2,868 live births were entered into the cohort (Gen2). These children, their parents, grandparents (Gen0) and now their own children (Gen3) form a unique multi-generational study, which has been helping researchers and policy makers better understand the causes of human health and well-being for more than 30 years.

After three decades, discoveries from the Raine Study continue to have significant impact on health policy, practice, and education around the world through ground-breaking multi-institutional research that examines influences, pathways and outcomes through all aspects of human life.



What we do

Initially known as The Western Australian Pregnancy Cohort (Raine) Study, the Raine Study came about as a result of a chance meeting between lead investigator Professor John Newnham and representatives of the Raine Medical Research Foundation. The Foundation was seeking to award a sizeable grant to one large-scale visionary project.

John and his co-investigators Professor Fiona Stanley, Professor Lou Landau and Professor Con Michael set to work on the grant application with two objectives: firstly, to develop a long term cohort to study the role that early life events (from the womb onwards) had on later life; and secondly, to investigate the effects of frequent ultrasound scans during pregnancy. This first aspect would be funded by the Raine Medical Research Foundation, and the second component by a NHMRC grant.

Each of the pregnant women originally recruited to the study was allocated at random into one of two groups – Regular Care or Intensive Care. Those in the Regular Care group had a single ultrasound imaging study at 18 weeks' gestation, with further scans only if clinically indicated. The women in the Intensive Care group had ultrasound scans at 18, 24, 28, 34 and 38 weeks' gestation.

Once the babies were born, the focus of investigation moved to the child, to determine how events during pregnancy and childhood influence health in later life. Since their birth, we have followed up with our Gen2 participants at regular intervals, at 1, 2, 3, 5, 8, 10, 14, 17, 18, 20, 22, 27 and 28 years of age. This has enabled us to develop an increasingly rich source of consistent longitudinal data for local, national and international researchers.

Each of these follow-ups has added exponentially to an increasingly powerful pool of data used to provide better education and global advancements in medical practice and research, uniquely impacting human health and quality of life:

- More than 30,000 pieces of data and over 30 million pieces of genetic information has been collected on each of our Gen2 participants.
- More than 500 babies have been born to the Raine Study Gen2 cohort – this number is estimated to reach 1,500 babies by 2030.
- Over 600 peer reviewed journal articles have been published using Raine Study resources in many of the world's leading scientific and medical journals.
- The Raine Study's data are a multi-institutional resource. Our researchers can be found in locations around the world, reaching far beyond the Raine Study's headquarters in Perth.

Our future

As we enter our fourth decade, the Raine Study's focus is on conserving and maximising use of these existing multi-generational data, as well as ensuring we are able to collect new data from our cohort and their families in the years and decades to come.





Organisational Structure

The Raine Study was initially managed through King Edward Memorial Hospital, then in early childhood its management shifted to what was then the Telethon Institute for Child Health Research (now Telethon Kids Institute).

In 2007, a Memorandum of Understanding was signed to establish a clear collaborative governance structure based on an Executive Committee chaired by the Dean of Medicine at the University of Western Australia and supported by a Scientific Director.

As the Raine Study participants matured, the offices for the Raine Study were moved to facilities at UWA in 2014.

Unincorporated Joint Venture

In 2017, following a review of the governance structure, it was decided to establish an Unincorporated Joint Venture which replaced the previous Raine Study Executive Committee.

The parties agreed to facilitate the development of an optimum governance structure for the Raine Study, developing a clear framework for the ownership, custodianship and control of assets of the Raine Study including data, biological samples and intellectual property.

The UJV is a collaborative partnership agreed between the **University of Western Australia, Curtin University, Edith Cowan University, Murdoch University, the University of Notre Dame Australia, Telethon Kids Institute**, and the **Women and Infants Research Foundation**.

The Raine Study's host is the School of Population and Global Health, headed by Professor Colleen Fisher, at The University of Western Australia.



Our partners



UJV Board Members

The Raine Study UJV Board is comprised of representatives of partners to the Unincorporated Joint Venture agreement, representatives of the Raine Study participant community (Gen1 and Gen2), and an independent Chair.

The role of the members includes attending regular meetings (three to four per annum), a commitment to be engaged in the initiatives and the outcomes being pursued by the Raine Study and to continue to advocate for the Raine Study.

In 2020, the members of the UJV Board were:

The University of Western Australia: Professor Tim Colmer

Curtin University: Professor Chris Moran



Edith Cowan University: Professor Margaret Jones, succeeded by Associate Professor Therese O'Sullivan

Murdoch University: Professor David Morrison

The University of Notre Dame Australia: Professor Gervase Chaney

Telethon Kids Institute: Adjunct Professor Paul Watt

Women and Infants Research Foundation: Deborah Attard-Portughes

Professor Peter Eastwood succeeded by Professor Romola Bucks (Director, The Raine Study)

Professor Anne Smith (Scientific Director, The Raine Study)

Aggie Bouckley (Operations Manager, The Raine Study)

Martin Becker (Gen1 Participant, The Raine Study)

Charlotte Diaz (Gen2 Participant, The Raine Study)

The Board is supported by Heather Campbell, Board Secretary.



Our People

Patron

The Honourable Kim Beazley AC, Governor of Western Australia

The Raine Study Patron is a distinguished individual who lends their support to the organisation and who has strong ties to Western Australia. The Honourable Kim Beazley became the Raine Study's patron in 2019 and has continued in this role since then.

Chair

Jan Stewart

The Raine Study UJV Board is chaired by an individual who is independent of all parties. The Chair is uniquely placed to advise the organisation and its Directors on strategic direction and overall performance. Meetings of the Board are convened by the Chair and supported by the Board Secretary. Jan Stewart has served as Chair of the Board since 2017.

Director

Professor Peter Eastwood succeeded by Professor Romola Bucks

The Director provides scientific and operational leadership to the Raine Study. This includes working to maintain the reputation of the Raine Study and a sustainable framework for the protection and continuation of the cohort in the future. The Director also enhances discovery by engaging high quality researchers, supporting the collection of new data and facilitating the utilisation of existing data as well as working to secure and maintain partner funding to cover core management costs. This is notionally a 0.2FTE position.

Scientific Director

Professor Anne Smith (January-June 2020)

The Scientific Director provides leadership and strategic direction for the Raine Study research activities. The Scientific Director's responsibilities include maximising utilisation of the Raine Study resources, maintaining productivity of high-quality researchers, establishing and maintaining national and international collaboration and creating research opportunities for the Raine Study. This is notionally a 0.2FTE position.

Scientific Advisor

Professor Leon Straker (departed June 2020)

The Scientific Advisor assisted the new Scientific Director with the transition to the new structure and personnel. As well as mentoring the new Scientific Director, they co-mentored the Science Manager, and provided strategic advice to the Director. The position was filled at 0.1FTE for 6 months.

Operations Manager

Aggie Bouckley

The Operations Manager has senior responsibility for all operational matters including finance, human resources and corporate support and oversight of operational issues related to cohort follow-ups, data and biosamples management, communications and participant engagement. The Raine Study Operations Manager reports to the Head of School of Population and Global Health and the Raine Study Director. This is a 0.8FTE position.

Administrative Officer

Heather Campbell, Jessica Parrotte (Andrews)

The Administrative Officer provides administrative support to operational and scientific activities in the leadership and management of the Raine Study. The Administrative Officer assists with research



processes, maintains the online submission system, updates the website, coordinates and takes minutes at meetings, assists with financial and human resource management as well as travel and event coordination and general office administration. This was a 0.8FTE position in 2020.

Communications Manager

Lorelei Campbell succeeded by Liz Rehfeldt succeeded by Kate Rowlands

The Communications Manager is responsible for promoting the Raine Study and providing effective external communications, developing key messages, branding and media releases targeting the community, government, researchers and participants. The Communications Manager consults regularly with the Raine Study Directors and research staff to develop plans and to advise on marketing and promotional strategies to enhance the Raine Study's reputation and improve stakeholder communications, engagement and retention. In 2020, the Communications Manager role was a 0.3FTE position. The position was vacated in January, filled in March; vacated again in July, and filled again in October.

Scientific Manager

Dr Juliana Zabatiero

The Scientific Manager works with the Scientific Director and the Director to provide support for the scientific aspects of the Raine Study including the Scientific Review Committee, the Special Interest Group Leaders and researchers, and research project management. In 2020 this position was 0.6FTE.

Scientific Support Officer

Monique Priston

The Scientific Support Officer supports researchers interacting with the Raine Online Submission System and provides support for the scientific aspects of all portfolios including the Scientific Management Committee and the Special Interest Group leaders and researchers, and the wider Raine Study researcher community. This was a 0.4FTE position.

Data and Biosamples Manager

Alex D'Vauz

The Raine Study Data and Biosamples Manager is responsible for the management and curation of the Raine Study longitudinal data and biosamples. They also advise the Raine Study leadership of strategic directions for data and biosample curation, ensuring high quality data and biosample collection, storage, and extraction for researchers, managing datasets, and providing support to researchers in relation to data requests. The Data and Biosamples Manager is also responsible for the supervision of data officers. This was a 0.6FTE position.

Data Officers

Huong Le, Marzieh Mehryar, Brendan Smith, John Langley, Nita Sodhi-Berry, Brigitte Burg, Sofyan Sahrom, Alisha Davis

The Data Officers are tasked with verification and accurate entry of scientific data relating to the Raine Study follow-ups, as well as the secure archiving and storage of the data. Their responsibilities include assisting with creating central quality-controlled data sets, data extraction requests, ensuring data quality, answering queries from researchers on data availability and assisting with the provision of feedback in a meaningful way to study participants. The Data Officers also provide support to the Data and Biosamples Manager role. The total FTE for the Data Officer role in 2020 was 2.9FTE.



Follow-up Manager

Diane Wood

The Follow-up Manager oversees coordination of all follow-up activities and ensures efficient and quality outcomes. They liaise with each follow-up coordinator to ensure consistency in procedures across follow-ups, pilot testing of data collection, provide updates along with study coordinators to lead investigators and work with the Raine Study team to coordinate all follow-up activities. The Follow-up Manager is responsible for ensuring a coordinated approach across all follow-ups to achieve the highest possible quality data and efficiency for the Raine Study. In 2020 this was a 0.1FTE position.

Senior Research Officer

Diane Wood

The Senior Research Officer coordinates the core Raine Study health assessments on cohort participants and other assessments on behalf of affiliated research projects. The senior research officer also trains research staff in the collection of data and ensures the smooth running of the cohort follow-up process. They are responsible for liaising with and recruiting the study participants and for the co-ordination of follow-up assessments including the protection of the study participants' interests, initial quality control of data collection, co-ordination, and scheduling of staff. In 2020 this position was 0.6FTE.

Participant Engagement Coordinator

Diane Wood

The Participant Engagement Coordinator coordinates participant engagement activities (formal and informal), advocates on behalf of participants, and is responsible for enhancing participant involvement and commitment to the Raine Study. They work with the Communications Manager, Operations Manager and Administrative Officer to develop strategies for enhanced engagement, effective communication, as well as ensuring maintenance, confidentiality, and the security of the cohort details. In 2020 this role was a 0.3FTE position.

Phlebotomist

Sue Green, Lilyana Beer

The Raine Study Phlebotomist is responsible for the collection of blood and other biological samples from the Raine Study participants. They are also responsible for assisting with recruitment and research administration for the cohort follow-ups. This was a 0.3FTE position in 2020.

Research Assistants

Monique Priston, Sue Green, Jacinta Saldaris, Beverley Hodgson, Kirsten Smith, Natalya Beer, Channa Marsh, Michael Furfaro

The Research Assistants are responsible for all aspects of data collection including physical assessment and questionnaire data from Raine Study participants. This includes the collection of anthropometry measurements, accelerometer data, blood pressures, DEXA and breast scans, the collection and processing of some biological specimens and the collection of questionnaire data. Research Assistants also have responsibility for the recruitment, booking and co-ordination of the study participants, and gaining consent from participants. In 2020, 7 Research Assistants worked on a casual basis between 3 and 15 hours per week including Saturdays.

Administrative Assistants (Research)

Jessica Parrotte (Andrews), Michael Trown

Two Administrative Assistants Research (AAR) worked to recruit participants for the Gen2-28 year Vision and Vessels follow-up as well as the Gen0 and Gen1-28 year Breast Density TiBS study. The AARs worked during the day and during evenings contacting, vetting, informing and booking participants to attend appointments. Combined, both roles accounted for 1.1FTE in early 2020.

Students

In 2020, there were 66 students working with the Raine Study, the majority enrolled in Doctor of Philosophy (PhD) degree and Masters degrees (Figure 1).

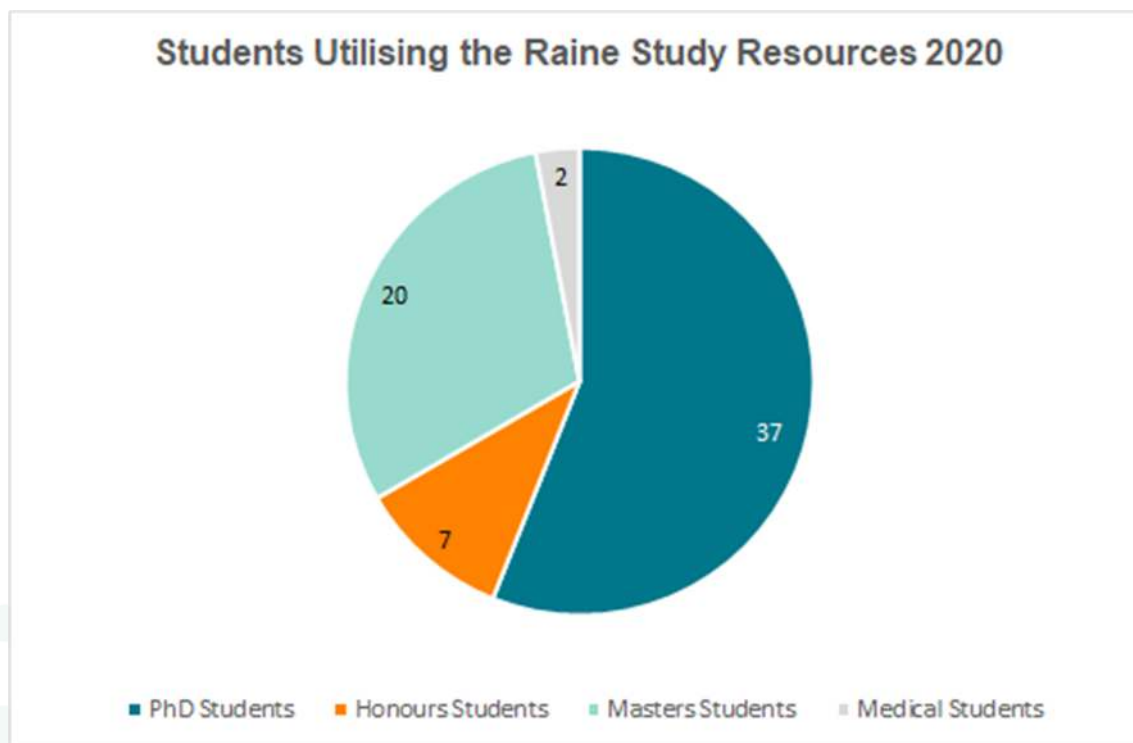


Figure 1. Students, degrees by type, that who have utilised the Raine Study resources in 2020

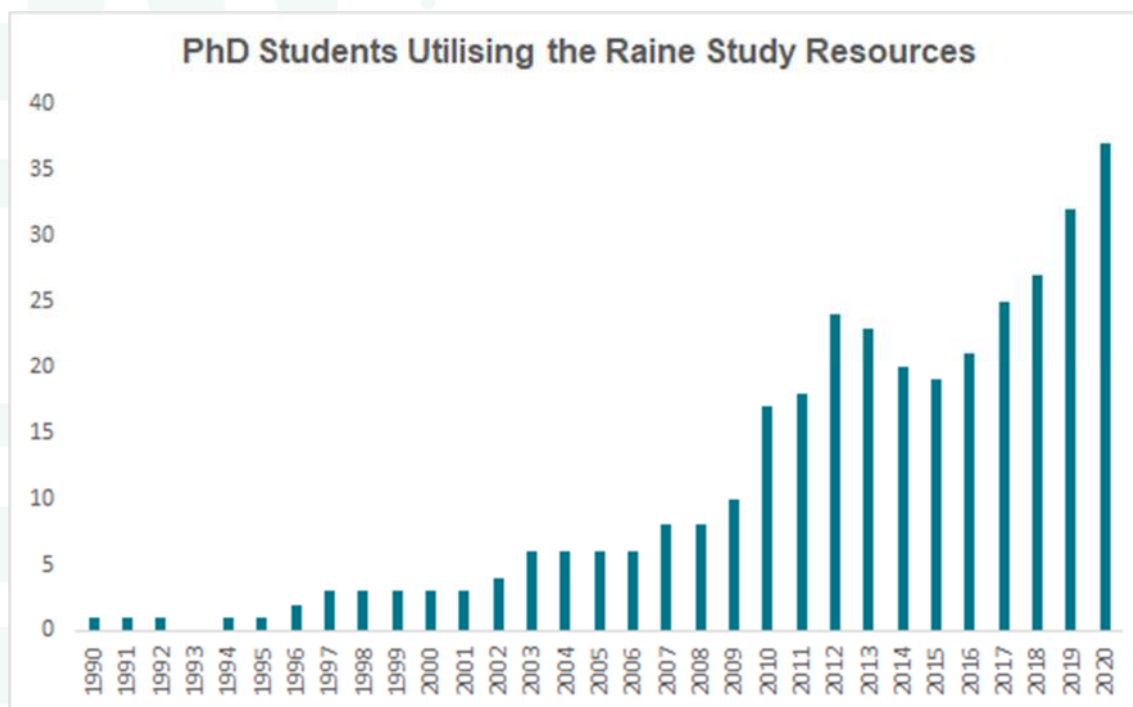


Figure 2. Number of students enrolled in a PhD program, who utilised the Raine Study resources, per year.



Committees

Scientific Management Committee

The Scientific Management Committee manages all science-related activities for the Raine Study and is comprised of the Scientific Director, Scientific Manager, Scientific Advisor, Director, Data and Biosamples Manager, Follow-up Manager, Scientific Support Officer and the Operations Manager.

Members in 2020 were Professor Anne Smith, Dr Juliana Zabatiero, Professor Leon Straker, Professor Peter Eastwood, Alex D'Vauz, Diane Wood, Monique Priston and Aggie Bouckley.

Scientific Review Committee

The Scientific Review Committee was set up to provide a high-quality review of scientific projects and science strategy. The members provide expert advice on science, feasibility and significance of proposed projects, input on processes supporting and monitoring science activity, and input on curation and utilisation of biosamples and data.

In 2020, membership was comprised of Professor John Newnham, Professor Lawrence Beilin, Dr John Blakey, Professor Megan Galbally, Professor David Mackey, Professor Susan Prescott, Professor Trevor Mori, Associate Professor Rae-Chi Huang, Dr Johnny Lo, Dr Phillip Melton, Professor Peter Eastwood, Professor Leon Straker, Dr Juliana Zabatiero, Rachael Wilkinson (Gen2 Participant) and Dr Alison Kerr (Gen1 Participant).

Special Interest Group Leaders Committee

The leaders of each Special Interest research Group are a team of 2-3 people representing a specific specialist area, who have been selected and appointed by the Raine Study Directors. They work with the Raine Study team to maximise the utility and utilisation of data in their area of expertise. They guide researchers interested in their area to expand activities and look to identify new expertise and researcher talent to; attract to the SIGs (local, national and international); advise on opportunities to collaborate with other SIGs; attract new research projects; attract new funding opportunities; and create student research opportunities.

The Raine Study SIG leaders in 2020 were:

Dr Phillip Melton, Professor Craig Pennell, Dr Koya Ayonrinde, Professor Trevor Mori, Dr Peter Franklin, Dr Rachel Foong, Dr John Blakey, Dr Melanie Walls, Professor Roger Hart, Professor Martha Hickey, Dr Rob Waller, Associate Professor Peter Kent, Dr Ashleigh Lin, Dr Monique Robinson, Dr Chris Brennan-Jones, Adjunct Professor Rob Eikelboom, Professor David Mackey, Professor Peter Eastwood, Professor Leon Straker, Associate Professor Joanne McVeigh, Dr Nigel McArdle, Associate Professor Therese O'Sullivan, Professor Wendy Oddy, Dr Robert Tait, Professor Rachel Skinner, Dr Shin Lee, Dr Paul Koshy, Dr Lynette Vernon, Associate Professor Patrick Dunlop, Angela Jacques, Professor Max Bulsara and Professor Anne Smith.

Community Advisory Committee

The Community Advisory Committee's function is to provide input and a community perspective into the Raine Study activities. They are tasked with contributing ideas to enhance participant engagement, identify areas of research that may be important to the Raine Study community, and provide feedback on the relevance, understanding and value of the research. The committee was established to provide an important link to researchers with the Raine Study participant community.

Members in 2020 were Martin Becker, Charlotte Diaz, Rachael Wilkinson, Dr Alison Kerr, Dr Ditza Teng, Jan Lettenmaier, Claire Adams, Cornel Scheibling, Janet Scott,



Roland Kerr, William Aitken, Rosanna Candler, Lori Fendel Sacks, Lucia Illich, Yhana Lucas, Richard Page, Ruth Page, and Dion Saratsis. The Raine Study's Operations Manager, Aggie Bouckley, provides support as committee secretary.

Additionally, Martin Becker and Charlotte Diaz represented the Community Advisory Committee on the UJV Board, Cornel Scheibling and Claire Adams on the Operations Management Committee, and Dr Alison Kerr and Rachael Wilkinson on the Scientific Review Committee.

Operations Management Committee

The Raine Study Operations Management Committee ensures communication and coordination between operational and scientific components and assumes overall responsibility to facilitate the effective management and operations of the Raine Study in the key areas of administrative and financial support. The Raine Study Operations Management Committee comprises of the Operations Manager, Director and Scientific Director, a community participant from Gen1 and Gen2, the Scientific Officer/Manager, the Project Officer/ Scientific Support Officer, the Follow-up Manager and Participant Engagement Coordinator, the Data and Biosamples Manager, the Communications Manager, and is supported by the Administrative Officer.

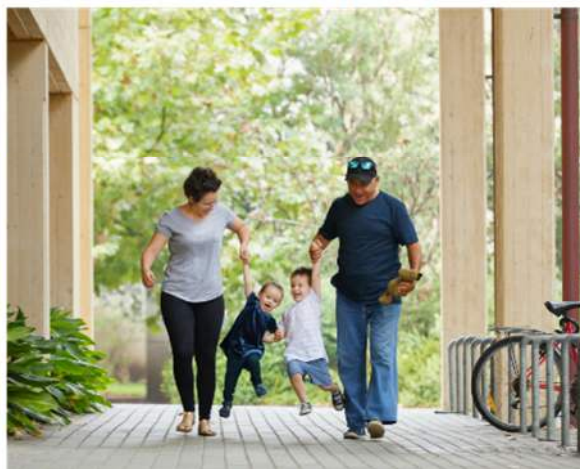
Members in 2020 were Aggie Bouckley (Chair), Professor Peter Eastwood succeeded by Professor Romola Bucks, Professor Anne Smith, Cornel Scheibling (Gen1 Participant), Claire Adams (Gen2 Participant), Dr Juliana Zabatiero, Diane Wood, Alex D'Vauz, Monique Priston, Lorelei Campbell succeeded by Liz Rehfeldt succeeded by Kate Rowlands, and Secretary Heather Campbell.



Participants

The original Raine Study babies (Gen2) were, on average, turning 30 years of age in 2020, and many have started having children of their own.

A total of 2,037 of our Gen2 remain registered as “active” participants, meaning that they have agreed to remain in the study and be contacted for future assessments. The Raine Study has contact details for 3,753 Raine Study parents (Gen1) and, to date, 715 offspring (Gen3) have been born to the Gen2 participants and registered with the Raine Study.



In March 2020, data collection and participant attendance at appointments for the Gen2-28 year follow-up was completed as planned. The impact of COVID-19 on booking numbers was evident in late February and March with a greater number of participants reluctant to attend a face to face appointment during that time. A total of 1,003 Gen2s participated - 868 attended an appointment, and 135 completed online questionnaires only.

The Gen0 and Gen1-28 year Breast Density TiBS study data collection was completed at the end of 2019. During the first quarter of 2020, project staff were finalising data entry and performing quality control on the collected data.



Funding for the Raine Study

The Raine Study UJV partners contribute annually to the core management costs of the Raine Study. UJV partners include the University of Western Australia, Curtin University, Edith Cowan University, Murdoch University, the University of Notre Dame Australia, the Women and Infants Research Foundation, and the Telethon Kids Institute. Annual funding is also received from the Raine Medical Research Foundation.

The Raine Study also generates income by charging data access and curation fees.

Grant Applications 2019 (for 2020 funding)

Twenty-five (25) grant applications totalling AU\$21.9 million were prepared and submitted in 2019 for research projects to commence in 2020, of which four (4) were successful totalling AU\$5.9 million.

Funded

1. Medical Research Council (UK) Career Development Award. E Winpenny. Early adulthood education/employment transitions and the development of inequalities in diet quality and cardiovascular health. GBP£500,007.
2. NHMRC Ideas Grant 1186123. D Dumuid, T Olds, M Wake, F Neumann, RS Kenett, D Foster, Z Pedisic, F Fraysee. Optimising Time Use for Health and Wellbeing. AU\$950,000.
3. The British Academy - BA/Leverhulme Small Research Grant SRG1819\190620. G Richards. Do foetal testosterone and maternal gestational Vitamin D levels predict hand preference at 10- and 16-years of age in the Western Australian Pregnancy Cohort (Raine) Study? GBP£3,079.
4. NHMRC Centres of Research Excellence 1198304. CB Nelson, P McGorry, S Wood, GP Amminger, A Yung, C Middeldorp, M Wichers, N Koutsouleris, S Clark, A Lin. PRE-EMPT: Prediction of Early Mental Disorder and Preventive Treatment Centre of Research Excellence. AU\$4,073,686.

Grant Applications 2020 (for 2021 funding)

Eleven (11) grant applications totalling AU\$7.4 million were prepared and submitted in 2020 for research projects to commence in 2021, of which two (2) were successful totalling over AU\$3.1 million. We await the outcome of a further 3 at April 2021.

Funded

1. Big Data Strategic Alliance between University of Oxford and Novo Nordisk. A Doherty. Using data from wearable devices to identify novel targets for cardiometabolic disease (obesity, T2DM, NAFLD, & heart failure). GBP£1,251,380.
2. NHMRC Ideas Grant 2003606. D Green, A Haynes, J McVeigh, L Naylor, G Hillis, K George. Identifying the Optimal Age to Apply Physical Activity Interventions to Improve Heart Health. AU\$945,620. AU\$ 852,804.

The following diagrams represent the total number of submitted and successful Raine Study grant applications since 2009 (Figure 3). The total amount awarded per year to Raine Study grant applications since 2009 is shown in Figure 4.

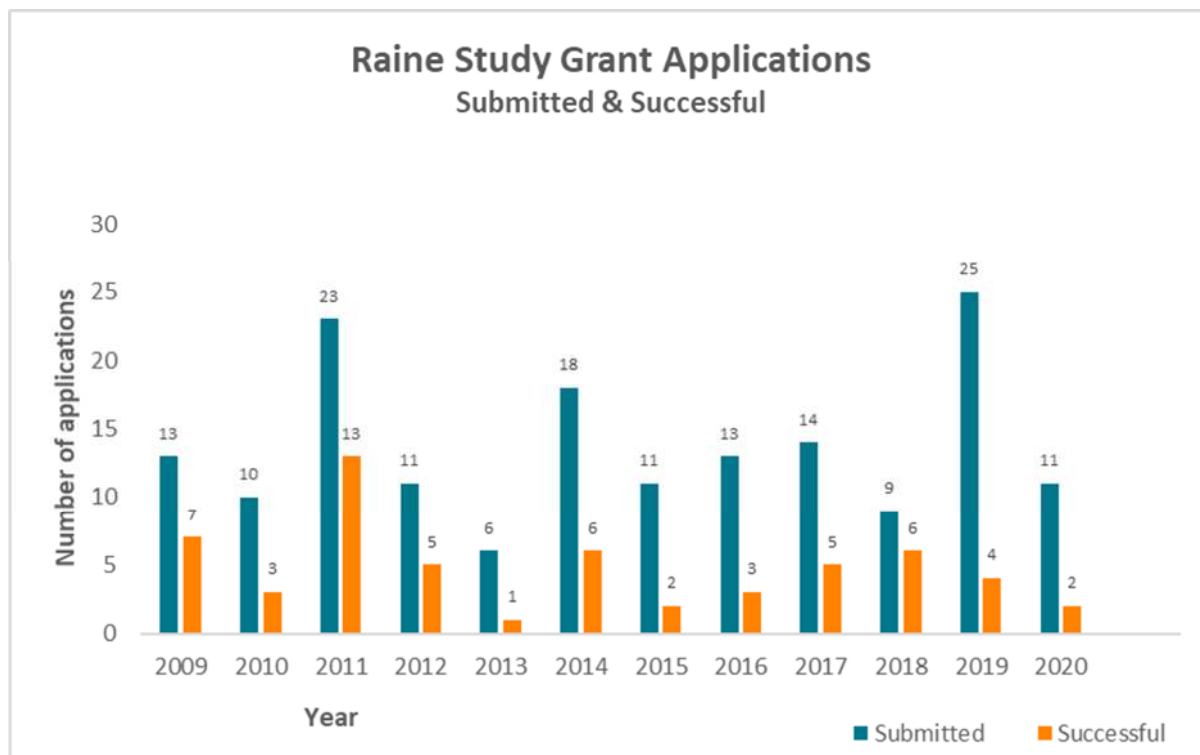


Figure 3. Number of submitted and successful grant applications per year

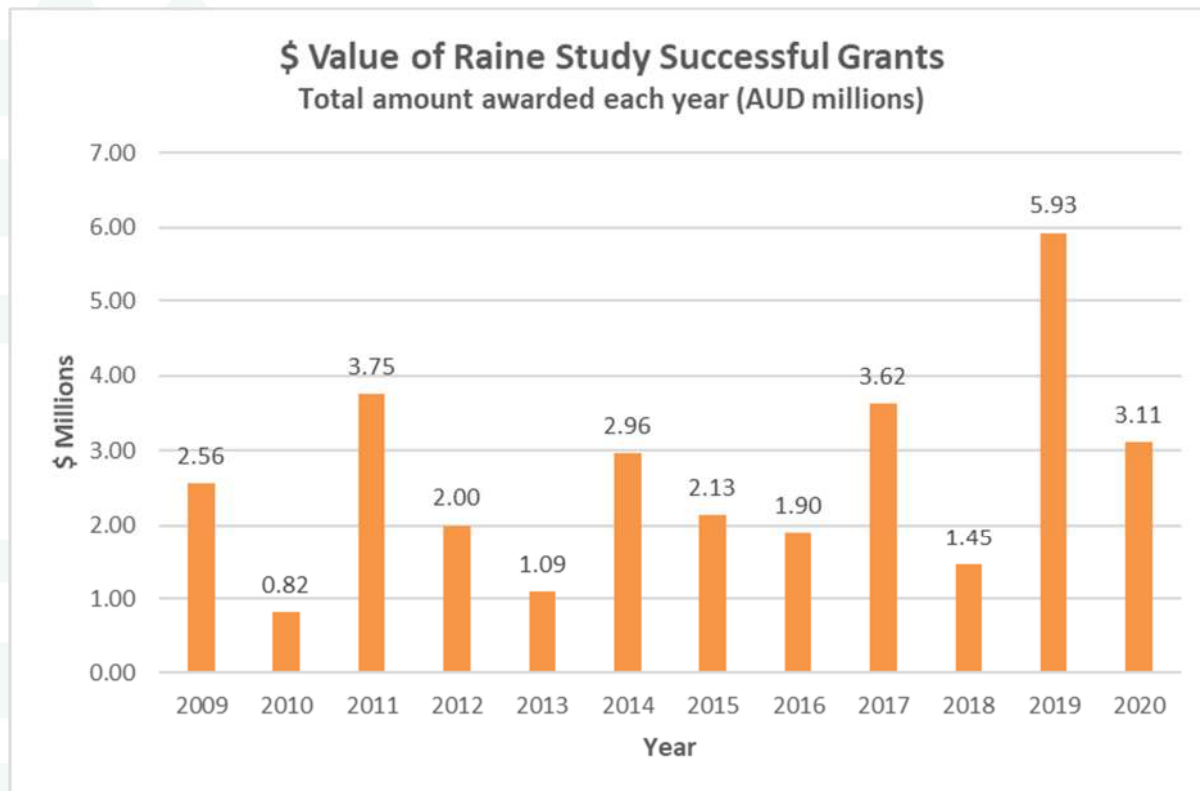


Figure 4. Total amount (\$millions) awarded to successful grants per year



Grant Funded Activities Update 2020

NHMRC Project Grant, 1161445. R Skinner, J Marino, S Lymer, D Doherty, K Steinbeck, L Straker, M Kang, R Tait. The health, social and economic implications of risk-taking in adolescence over the life-course: a data linkage study of the Raine Study cohort. A\$1,061,015.

Much of the burden of disease and social adversity in adulthood arises from long-standing patterns of health-related risk behaviour and lifestyle, which begin in childhood and adolescence. We are linking the Raine Study questionnaire and physical examination data to long-term outcomes recorded in datasets kept by the Western Australian Departments of Health and of Education. We are modelling pathways of sexual risk behaviour, substance use, and certain mental health problems from childhood through adolescence, and will use those to estimate the health costs and productivity losses associated with these health-related risk behaviours. This work will be used to inform cost-efficient preventive efforts. No new data collection from the Raine Study participants is needed for this work. In 2020, the team continued working on data analyses.

ARC Discovery Project, DP150103312. S Parker, P Dunlop, L Straker, K Parkes, Work design matters: The dynamic interplay of work and person factors, \$334,119.

This project aims to examine the working environment and how this affects an individual's health, work performance and behaviour. The study looks at how personality and demographics, and their interactions, shape or constrain individuals' opportunities to undertake high quality work and vice versa. It also examines how family, education, and workplace factors affect the individual and their workplace. The Raine Study participants' contact details were updated and the questionnaires were sent out in May 2016. All active Raine Study Gen2 participants were contacted and invited to complete an online questionnaire in relation to themselves and their workplace. 472 participants completed their questionnaires. In addition to that, 63 managers and 69 peers completed a questionnaire about the Raine Study participants. In 2018 the follow-up questionnaires were sent to Gen2 participants, with 221 of the original 477 respondents and 114 new Gen2 participants responding. In 2020, data analyses and reporting continued, with one manuscript published and another in preparation.

NHMRC 1102106, 2016-2020, T Mori, L Beilin, E Moses, G Watts, L Adams, Genetic and early life predictors of ectopic fat and their association with cardio metabolic health and disease, \$1,706,136. The grant application has helped fund the Gen2-27 year follow-up and aims to examine the genetic, antenatal and childhood antecedents of ectopic fat depots in young adults, and the relative importance of different depots in relation to cardio metabolic health and novel markers of resolution of inflammation. Ectopic fat depots are best quantified using Magnetic Resonance Imaging (MRI). The follow-up commenced in May 2016. Eligible participants were invited to participate in a physical assessment and an MRI. The physical assessment tests include the core anthropometric measurements of height, weight, skinfolds and blood pressure, DXA scan as well as a repeat of some of the eye measurements from the year 20 follow-up. Fasting bloods were also obtained on the day of their assessment and for females a new breast density screening test using Transillumination Breast Spectroscopy (TiBS) was also performed. All participants were also requested to provide urine and faecal samples. Data collection was completed in December 2018 with 1082 participants providing some data and 975 completing the abdominal MRI. In 2020, data analyses and reporting continued, with manuscripts in preparation.

NHMRC Project Grant, 1126494. D Green, L Beilin, L Straker, P Eastwood, T Mori, P Ainslie. Developmental Origins of Adult Cardiovascular Disease: Vascular Health in the Raine Cohort. A\$1,087,427.

The evidence-base to establish early intervention targets for the prevention of future cardiovascular disease is not well established and the relative importance of the foetal environment, in relation to risk factor exposure during childhood and adolescence, is unclear. The grant application has helped fund the Gen2-28 year follow-up and aimed to utilise longitudinal data collected on children and their families in



the Raine Study to assess the prevalence and risk factors for arterial health in participants at 28 years of age. Participants will undergo comprehensive non-invasive assessments of arterial function/structure which are pre-clinical indices of atherosclerosis that predict cardiovascular events. This project represents a unique opportunity, with a birth cohort with detailed phenotypic and environmental data followed from birth through to early adulthood in whom we can now apply sophisticated non-invasive imaging technologies for assessment of pre-clinical cardiovascular disease (CVD) and its precursors. Data collection for the Gen2-28 year Vision and Vessels follow-up started in 2018 and was completed in 2020, with 1003 participants included and 250 participants completing measures related to this grant. Data analyses and reporting are underway.

NHMRC Project Grant, 1121979. Young adult myopia: genetic and environmental associations. D Mackey, A Hewitt, C Hammond, S MacGregor, K Rose, E Milne, R Lucas, F Chen, M He, J Guggenheim. A\$809,207.

The Gen2-20 year follow-up of Raine Study has established the Western Australia population data in myopia and pterygium. The next level of our research is to identify associations of other ocular biometry, genetic and environmental risk factors involved in development and progression of these ocular disorders as well as confirming already identified associations. Currently, there is very little ocular data in this age group. Associations of conjunctival UV autofluorescence (CUVAF), education, Vitamin D levels, related immune biomarkers, bone density and other sun exposure factors are not well understood. No data exists on longitudinal progression of these disorders therefore this cohort will establish the first study in ocular epidemiology. The grant application has helped fund the Gen2-28 year follow-up and aimed to (1) identify changes in myopia prevalence and related ocular biometry, (2) identify changes in prevalence of pterygium and sun measures, and (3) identify changes in optic nerve structure which is important parameter to understand development of glaucoma, insidious eye disease that cause peripheral vision loss later in life. Data collection for the Gen2-28 year Vision and Vessels follow-up started in 2018 and was completed in 2020, with 1003 participants included and 815 participants completing the measures related to this grant. Data analyses and reporting are underway.

Cancer Australia PdCCRS. J Stone, C Saunders, L Lilge, D Sampson, M Hickey, G Cadby, J Shepherd, M Giorgi, M Cook. Measuring breast density in younger women to inform primary prevention and early detection of breast cancer. \$592,636.

Breast density is a strong predictor of breast cancer risk. Evidence of this has been derived from mammography, which is not recommended for younger women. New methods of measuring breast density are therefore needed to bridge large gaps in knowledge regarding breast density in young women. Members of the research team have developed Transillumination Breast Spectroscopy (TiBS) which measures spectral differences in breast composition using visible and near infrared light. It correlates highly with mammographic breast density in women over 40 and is safe and easy to use. The grant application has helped fund the Gen2-28 year follow-up and aimed to (1) obtain both TiBS and mammographic breast density measures (via linkage with BreastScreen WA) for the Raine Study Gen0 and Gen1 participants to further validate TiBS breast density against mammographic breast density in an Australian population; (2) develop a TiBS breast density score that could be standardized (e.g. by age) and used to derive the normal distribution of breast density for Australian women aged 18-40 using data from Gen2-28 year follow-up, (3) estimate the heritability of the TiBS score within families and its association with known genetic determinants of mammographic breast density and we will use data from Gen2-28, Gen0 and Gen1, and (4) obtain repeated TiBS breast density measures (from Gen2-27 and Gen2-28 year follow-ups) to prospectively identify environmental and life style factors associated with change in TiBS breast density within younger women. In 2020, data collection was completed on 452 Gen1, 84 maternal Gen0, and 25 paternal Gen0 participants.



National Heart Foundation 102170. A Haynes, L Taylor, D Green, L Straker J McVeigh. Developmental origins of adult myocardial structure and function: heart health and the Raine Study Cohort. A\$75,000.

This grant allowed a new outcome measure (heart structure and function by echocardiography) to be included in the Gen2-28 year follow-up which was already underway. The aim of this project was to investigate whether physical activity in childhood and adolescence had any lasting influence on heart structure and function in adulthood. Data collection occurred throughout 2019 and 2020, during which time 232 participants received an echocardiogram. Data analyses and reporting are underway. In 2020, preliminary analysis of heart function data has been completed and a manuscript submitted for publication.

WAHTN-MRFF. L Straker, P Eastwood, D Glance. Supporting governance, discovery and translation from large health datasets: development of a research project online management system to support strong governance and translation from health studies. A\$146,165.

The Raine Study had developed an IT system for the management, translation and dissemination of all research projects using the Raine Study resources, called the Raine (Study) Online Submission System (ROSS). This system was effective, but rudimentary in nature.

The project funded by the WAHTN iteratively developed a refined and vastly improved ROSS system (ROSS v2.0) based on user reviews by Western Australian, national and international researchers, user reviews by management staff of the Raine Study and other large studies, and technical functionality reviews by IT experts.

The project was finalised in 2020 and its outcome is a refined ROSS system with demonstrated improvements in user friendliness and technical capacity and robustness. This upgraded system can facilitate better project management for both researchers and management staff – from project application to the reporting of the results. This supports stronger governance of projects and enables translation of trustworthy evidence to advance knowledge and enhance lives.

Projects Update

New applications to use the Raine Study data

In 2020 there were 69 new project applications, 129 new data access and biosample requests, 85 new manuscript proposals, and 65 new manuscripts submitted in ROSS (Figure 5).

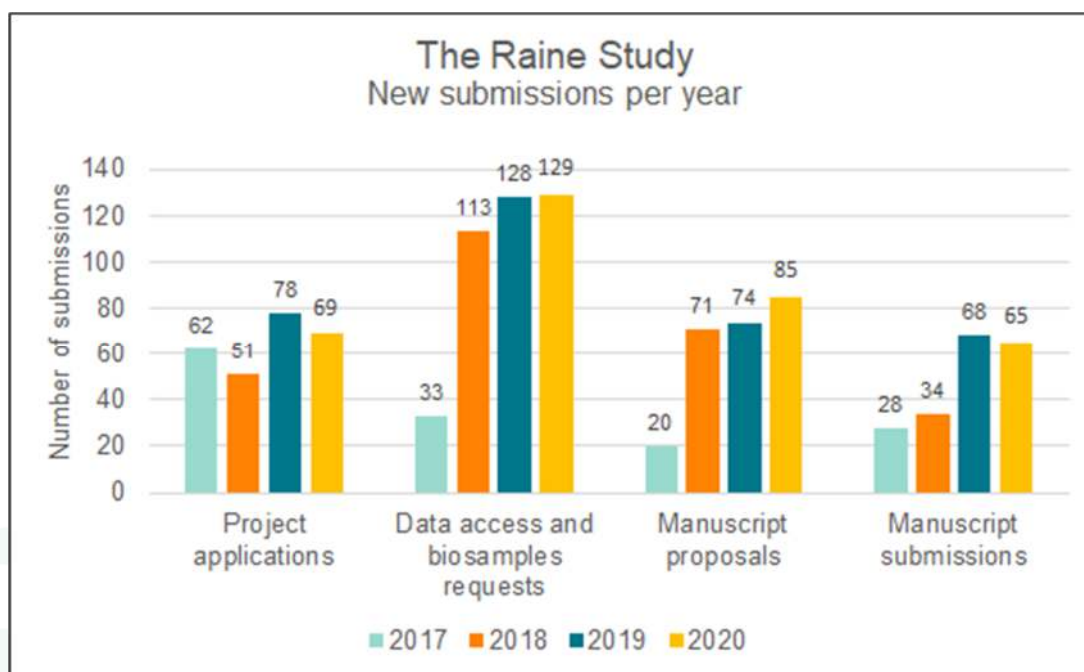


Figure 5. Number of Raine Study new submissions per year.

Data collection completed during 2020

Generation 2 Data Collection

- Gen2-28 year follow-up (Vision and Vessels): 1,003 participants completed some data collection, with 815 participants completing the vision-related measures; 577 participants completed the vessels-related measures; 828 participants completed the core health checks, and 135 participants completed questionnaires only. Data collection was finalised in March 2020.



Translation, Dissemination & Impact

Publications

In 2020, 49 peer-reviewed papers were published (includes e-publications ahead of print) bringing the total for the Raine Study Publications to 599 (Figure 6), with over 93% of these in journals with impact factors of 2 or greater (Figure 7). High Impact publications included those listed in Appendix 3.

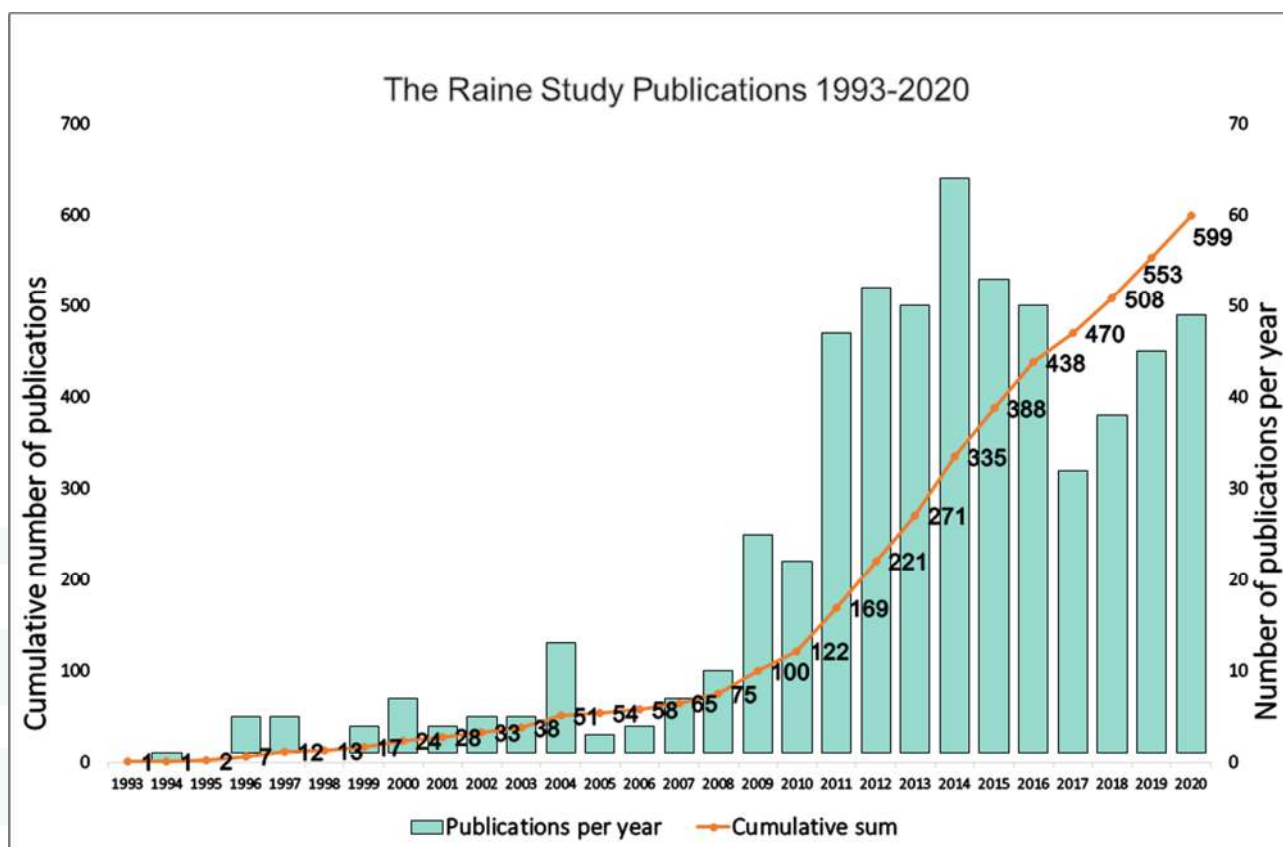


Figure 6. Number of Raine Study publications by year (1993-2020)

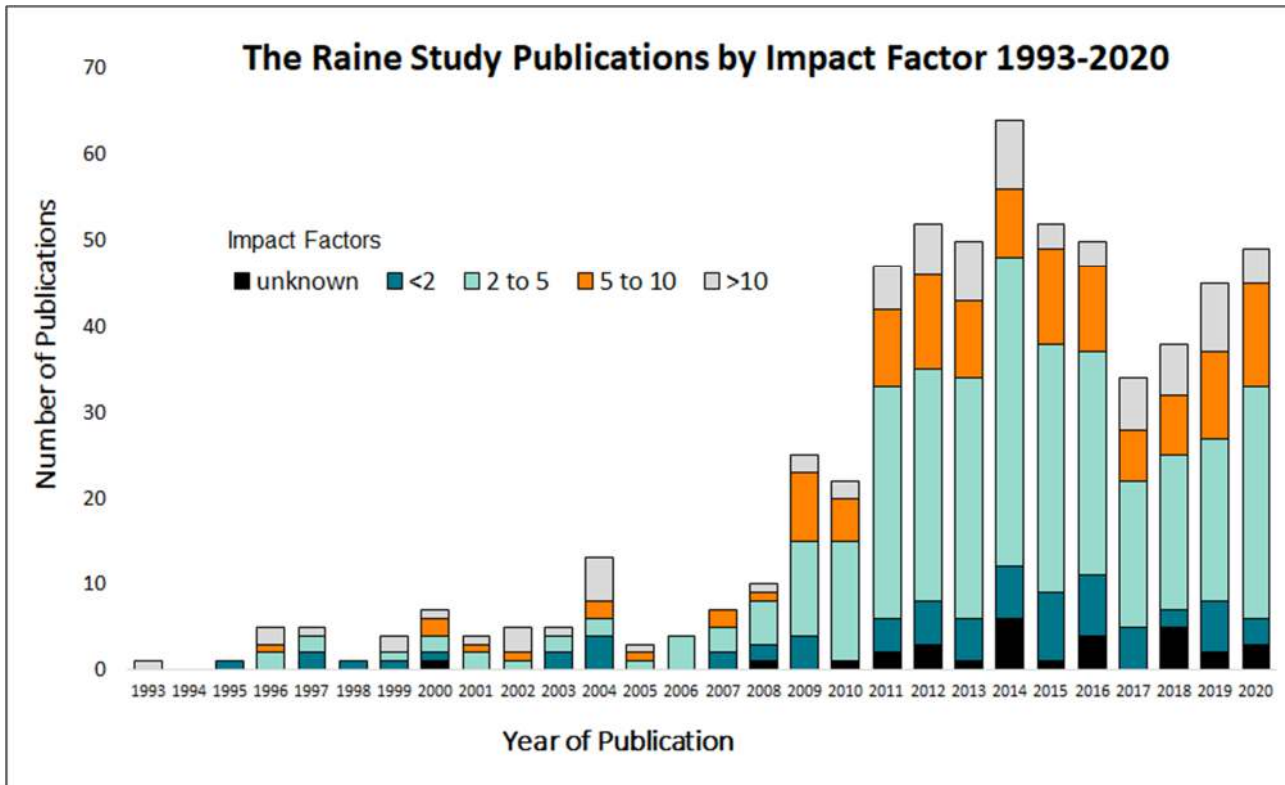


Figure 7. Number of The Raine Study publications by year and impact factors

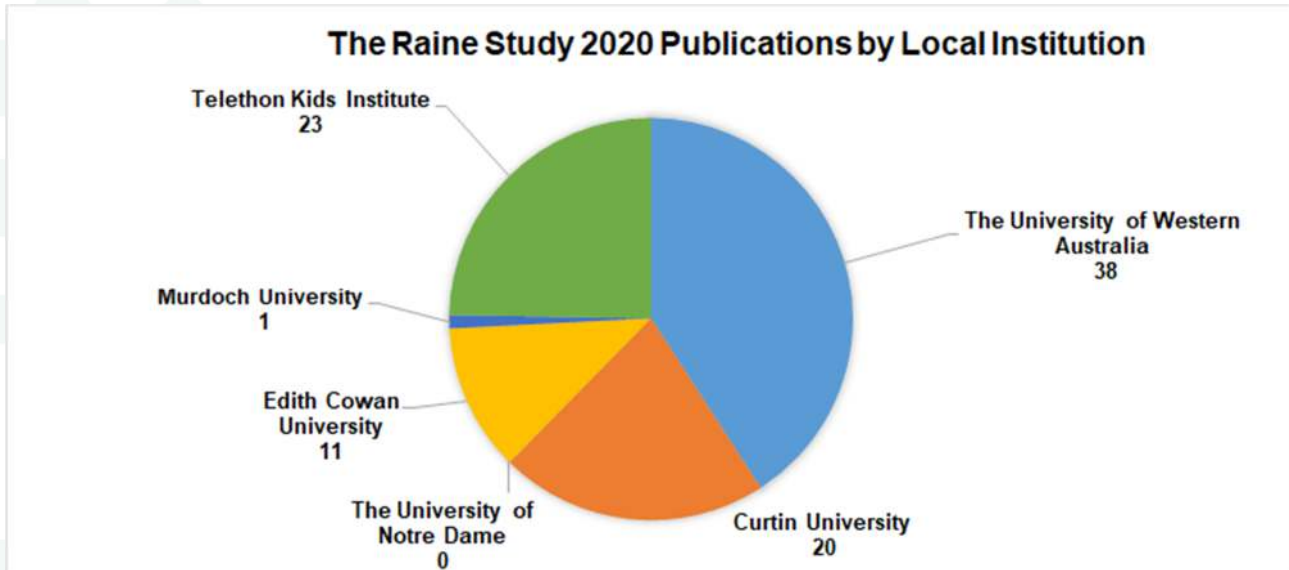
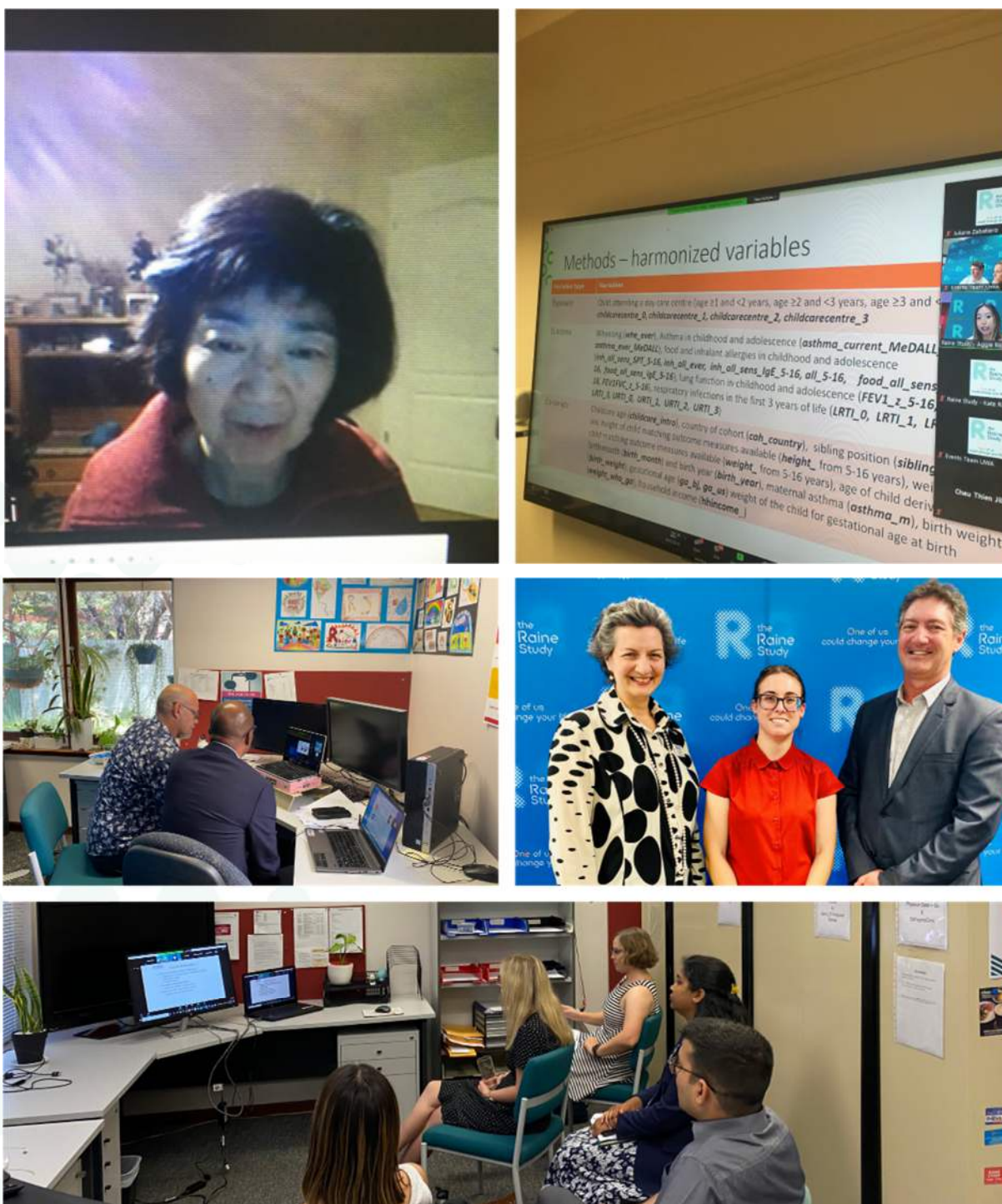


Figure 8. Number of Raine Study publications in 2020 by local institution

External Events and Engagement

The Raine Study 13th Annual Scientific Meeting (ASM) 2020

Despite the uncertainty caused by pandemic conditions during the planning of the 2020 ASM, the team displayed great agility to present the Raine Study's 13th Annual Scientific Meeting for the first time as a blended event, combining virtual and in-person elements.



From top: Virtual presentations, session chairs, markers and audience members at the 2020 ASM



The event was a great showcase of the breadth and depth of the Raine Study research that is taking place across our UJV partners. 16 early career researchers from around Australia and 1x international location presented at the event either via Zoom (9 ECRs) or in-person (8 ECRs).

More than 81 unique users logged into the ASM via Zoom. In addition, more than 40 attendees came to Raine House to participate in person on the day of the event, which presented visitors with excellent networking opportunities during the morning tea and lunch breaks, as well as after the event had closed.

Four of our UJV partners (Curtin, Murdoch, TKI, UWA) were represented among the 6x session chairs. Board Chair Jan Stewart introduced founding Raine Study Investigator Professor John Newnham, who provided an entertaining and informative keynote address which shed new insights on the Raine Study's 30-year history. Associate Professor Chris Abbiss (ECU) opened the afternoon session with an update on the research priorities of ECU's School of Medical and Health Sciences, while outgoing director of the Raine Study Professor Peter Eastwood provided commentary throughout the day.

Dr Amanda Cleaver, Director of our longstanding partner the Raine Medical Research Foundation, presented the awards for the two Best Early Career Researcher presenters. The recipients were Dr Samantha Lee from Lions Eye Institute and Dr Chau Jillian Thien Tay from Monash University. Dr Lee presented research into the causes of choroidal (optic disc) thickness in young adults, while Dr Chau Tay spoke about updated diagnostic criteria for polycystic ovary syndrome based on Raine Study data.



RMRF ECR Presentation Award winners Dr Chau Jillian Thien Tay (L) and Dr Samantha Lee with the RMRF's Dr Amanda Cleaver (R)

Professor Eastwood closed the event with the formal introduction of the Raine Study's new/current Director Professor Romola Bucks to our scientific community.

The event was promoted extensively via social media, email marketing and on the Raine Study website, including the announcement of the RMRF ECR prize winners. This was the first time a blended event combining virtual with in-person participation had ever been attempted by the Raine Study team. The resounding success of the event under these circumstances was not a given and has provided many key learnings which will be applied to the planning of the 2021 Scientific Meeting.



Early Career Researcher Presentations from the 2020 ASM

The following is the list of presentations made by early career researchers at the 2020 ASM using information from the Raine Study:

- The interaction between sleep apnoea and sleep duration on hypertension risk.
Ms Kelly Sansom, Prof Peter Eastwood, A/Prof Nigel McArdle, Dr Jennifer Walsh, Dr Kathleen Maddison, Clin/Prof Bhajan Singh.
- Maternal prenatal stress exposure and sex-specific risk of severe infection in offspring.
Dr Monique Robinson, Dr Kim Carter, Prof Craig Pennell, A/Prof Peter Jacoby, Dr Hannah Moore, Prof Stephen Zubrick, Prof David Burgner.
- The relationship between fetal growth during pregnancy and blood pressure in adulthood.
Dr Ashish Yadav, Emer/Prof Lawrie Beilin, Prof Trevor Mori, A/Prof Rae-Chi Huang, Mr Philip Vlaskovsky, Prof John Newnham, Dr Scott White.
- Prospective associations of sugar-sweetened beverage consumption during adolescence with body composition and bone mass in early adulthood.
Mrs Amrei Bennett, Dr Kevin Murray, Dr Gina Ambrosini, Prof Wendy Oddy, Prof John Walsh, A/Prof Kun Zhu.
- Association between pelvic pain and pain sensitivity in young women.
Ms Lindsay O'Kane, Dr Darren Beales, Mrs Renata Asinelli, Mrs Marit Klokset, Mrs Tonje Urstad, Mrs Emma Wise, Dr Juliana Gomes Zabatiero, Dr Judith Thompson, Dr Jennifer Pontre, Dr Robert Waller.
- Changes in the epigenetics of suicide ideators but not victims of childhood bullying.
Dr Ee Pin Chang, Prof Andrew Page, Dr Phillip Melton, A/Prof Rae-Chi Huang.
- Prospective association between dietary fats and fatty liver index trajectories in a longitudinal cohort population: an 8-year follow-up study from adolescence to young Adulthood.
Dr Fuzhen Wan, Dr Feng Pan, Dr Oyekoya Ayonrinde, A/Prof Leon Adams, Prof Trevor Mori, Emer/Prof Lawrie Beilin, A/Prof Therese O'Sullivan, Prof John Olynyk, Prof Wendy Oddy.
- Personalised, machine learning based prediction of asthma in Western Australia.
Mrs Dimpalben Patel, Prof Graham Hall, Dr Rachel Foong.
- Correlation between aldosterone renin ratio and blood pressure in young adulthood: a longitudinal study.
Dr Jun Yang, Dr StellaMay Gwini, Prof Lawrie Beilin, Prof Markus, S Schlaich, Prof Michael Stowasser, A/Prof Morag Young, Prof Peter Fuller, Prof Trevor Mori.
- Do early life chronic inflammatory conditions predict low back pain in adolescence and young adulthood?
Ms Amber Beynon, Prof Bruce Walker, Prof Jeffrey Hebert, Dr Darren Beales, Ms Angela Jacques.
- Early-life predictors of lung function trajectories in the Raine Study.
Ms Francesca Sanna, Dr Rachel Foong, Prof Graham Hall, Dr Francesca Locatelli, Dr Elisha White, Prof Peter Sly.
- Early-life day-care attendance is associated with increased wheeze symptoms in the first 5 years of life but not asthma in later life.
Dr Rachel Foong, Ms Jennie Carson, Prof Peter Sly, Prof Graham Hall, A/Prof Rae-Chi Huang.
- Twelve-year sleep trajectory from childhood to adolescence: associations with myopia and ocular biometry during young adulthood.
Mr Nicholas Stafford Bell, Dr Gareth Lingham, Prof David Mackey, Dr Seyhan Yazar, Prof Peter Eastwood, Prof Leon Straker, Prof Anne Smith, A/Prof Joanne McVeigh, Dr Samantha Lee.



- Updated adolescent diagnostic criteria for polycystic ovary syndrome: impact on prevalence and longitudinal body mass index trajectories from birth to adulthood.
Dr Chau Thien (Jillian) Tay, Prof Roger Hart, Prof Martha Hickey, A/Prof Lisa Moran, A/Prof Arul Earnest, Prof Dorota Doherty, Prof Helena Teede, Dr Anju Joham.
- Associations between 7-year C-reactive protein trajectory and choroidal thickness in young Adults.
Dr Samantha Lee, Dr Darren Beales, Dr Fred Chen, Dr Seyhan Yazar, Dr David Alonso-Caneiro, Prof David Mackey.
- Dietary intake and major food sources of flavonoids among Australian adolescents in the Raine Study.
Dr Katherine Kent, Prof Karen Charlton, A/Prof Therese O'Sullivan, Prof Wendy Oddy.
- Parents' nonstandard work schedules and adolescent social and emotional wellbeing: Evidence from the Raine Study.
Dr Jianghong Li, Ms Hannah Kenyon Lair, Mr Jakob Schafer, Dr Garth Kendall.



Presentations

The following is a snapshot of the range of presentations made by researchers during 2020 using information from the Raine Study:

Professor Leon Straker:

- **Twelve-year sleep trajectory from childhood to adolescence: associations with myopia and ocular biometry during young adulthood.**
Stafford Bell, N., Lingham, G., Mackey, D., Yazar, S., Eastwood, P., **Straker, L.**, Lee, S. (2020).
Presented at The Raine Study 13th Annual Scientific Meeting, Virtual, 30 October 2020.

Professor Trevor Mori:

- **Correlation between aldosterone renin ratio and blood pressure in young adulthood: a longitudinal study.**
Yang, J, Gwini SM, Beilin LJ, Schlaich M, Stowasser M, Young M, Fuller P, **Mori TA.**
Presented at The Raine Study 13th Annual Scientific Meeting, Virtual, 30 October 2020.
- **Prospective association between dietary fats and fatty liver index trajectories in a longitudinal cohort population: an 8-year follow-up study from adolescence to young adulthood.**
Wan F, Pan F, Ayonrinde O, Adams LA, **Mori TA**, Beilin LJ, O'Sullivan TA, Olynyk JK, Oddy WH.
Presented at The Raine Study 13th Annual Scientific Meeting, Virtual, 30 October 2020.
- **Correlation between aldosterone renin ratio and blood pressure in young adulthood: a longitudinal study.**
Yang, J, Gwini SM, Beilin LJ, Schlaich M, Stowasser M, Young M, Fuller P, **Mori TA.**
Presented at the 63rd Endocrine Society of Australia Annual Scientific Meeting, Virtual, 31 October – 1 November, 2020.
- **The relationship between the aldosterone-to-renin ratio and blood pressure in young adults: a longitudinal study.**
Yang, J, Gwini SM, Beilin LJ, Schlaich M, Stowasser M, Young M, Fuller P, **Mori TA.**
Presented at the 2020 HBPRCA Virtual Annual Scientific Meeting, 3-4 December 2020.

Ashish Yadav – The Raine Study 2020 Scholarship Recipient

- **Are changes in fetal growth during pregnancy associated with blood pressure in later life?**
Yadav A, Mori TA, Beilin L, Huang R-C, Vlaskovsky P, White S, Newnham J.
Presented at the 2020 HBPRCA Virtual Annual Scientific Meeting, 3-4 December 2020.

Dr Samantha Lee – Co-winner, Best Early Career Researcher Presentation, The Raine Study 13th Annual Scientific Meeting:

- **Associations between 7-year C-reactive protein trajectory and choroidal thicknesses in young adults.**
Presented at The Raine Study 13th Annual Scientific Meeting, Virtual, 30 October 2020.
- **Associations between obstructive sleep apnoea and optic disc measures.**
Presented at the Raine Study Community Advisory Committee, Perth. 24 October 2020.
- **Associations between 7-year C-reactive protein trajectory and choroidal thicknesses in young adults.**
Presented at the Lions Eye Institute Research Group meeting, 11 August 2020
- **Sunlight, sleep, snores, and the silent thieves of sight.**
Presented at the UWA Research Bytes Series. 16 June 2020.



- **Choroidal thickness in young adults and its association with visual acuity.**
Presented at the World Ophthalmology Congress (WOC) Virtual. 16-19 June [in place of WOC 2020 because of the COVID-19 pandemic, originally planned to be held in Cape Town, South Africa].
- **Associations between obstructive sleep apnoea and the retinal nerve fibre layer thickness.**
Presented at the Australia and New Zealand Glaucoma Society, Adelaide 21 February 2020.

Dr Jason Charng

- **Age dependent retinal nerve fibre changes in SIX6-SIX1 polymorphism.**
Presented at the Australian and New Zealand Glaucoma Society, Adelaide. 21 February 2020.

Dr Gareth Lingham

- **Frequency of Retinal Nerve Fibre Layer Thickness Misclassification in Young Healthy Adults Using the Heidelberg Spectralis. Invited Speaker.**
Presented at the Orthoptics Australia online weekend 14-15 November 2020.
- **Influence of prenatal environment and birth parameters on amblyopia, strabismus, and anisometropia.**
Presented at the Orthoptics Australia Live Journal Club 8 July 2020.
- **Frequency of sectoral retinal nerve fibre layer thickness misclassification in a cohort of young healthy adults using the Heidelberg Spectralis reference.**
Presented at the Australia and New Zealand Glaucoma Society, Adelaide, 21 February 2020.

Professor David Mackey

- **Genes and environment: towards personalised prevention of myopia in children.** Keynote Speaker, Non-Strabismus Lecture.
Presented at the World Society of Paediatric Ophthalmology & Strabismus Worldwide Connect 2020, 3 October 2020
- **Genetics of myopia.** Invited speaker, Childhood Myopia session.
Presented at the 37th World Ophthalmology Online Congress, 29 June 2020.
- **Australia's low rate of myopia: outdoor exposure.** Invited speaker, Myopia: Treating the Epidemic session.
Presented at the 37th World Ophthalmology Online Congress, 27 June 2020.

Dr Monique Robinson

- **Pregnancy to Present Day: 30 Years of Mental Health Research I the Raine Study.**
Presented at The Raine Study Mental Health Webinar, 19 August 2020.
- **Maternal prenatal stress exposure and sex-specific risk of severe infection in offspring.**
Presented at The Raine Study 13th Annual Scientific Meeting, 30 October 2020.



Coverage of the Raine Study

It was a challenging year for the purposes of garnering mainstream media coverage for anything not directly related to the COVID-19 pandemic.

While the Raine Study was able to secure coverage early in the year on the back of the Lotterywest grant announced in late 2019, and news of Professor Anne Smith becoming our new Scientific Director in January 2020, there were few other proactive media opportunities until the announcement of Professor Romola Bucks' appointment as the Raine Study's new director in November 2020.

In addition, general awareness of the Raine Study received a boost when Professor John Newnham was named 2020 Senior Australian of the Year on 25 January 2020. John is a wonderful advocate for the Raine Study and mentioned us regularly in his media interviews. This resulted in mentions of the Raine Study on 9News, News.com.au and the ABC, among others. The Raine Study's website traffic also rose as a result of searches for information about Professor Newnham.

Page 34 - POST, November 21, 2020

Romola steers early life study

Professor Romola Bucks has been appointed director of the Raine Study, Australia's longest-running cohort study.

Established in 1989, it is one of the largest ongoing studies of the same group of individuals anywhere in the world, from before they were born, through early adulthood and beyond.

It is based at the University of WA as a joint venture between all of the WA universities.

Professor Bucks fills the vacancy created by Professor Peter Eastwood's appointment as director of the Flinders Health and Medical Research Institute in South Australia.

She started on November 2 and will take the study into its fourth decade.

One of her first tasks will be to recruit a new scientific director.

"I'm excited to join the Raine Study team, which was the first of its kind to investigate the impact of more frequent ultrasound on maternal and infant health," Professor Bucks said.

"Thirty years later, discoveries from the Raine Study have

had a significant impact on health policy, practice, and education across the globe.

"My goal is to maintain the reputation of the Raine Study and ensure that it can continue to provide the best evidence of early life predictors of health and wellbeing into middle and older age.

"Firstly, by conserving and maximising use of the more than 30,000 pieces of data we have already collected; and secondly, by ensuring we are able to collect new data from our cohort and their families as they enter their fourth decade."

Jan Stewart, chair of the Raine Study board, said the Raine Study was a uniquely valuable resource, not only in WA but in Australia and internationally.

"Romola's passion for science as well as her record of distinction as an academic and clinical psychologist and commitment to mentoring young scientists makes her the ideal person to lead the Raine Study into its next decade of life-changing discoveries," she said.

Currently a professor in the School of Psychological Science at UWA and formerly Deputy Dean of the Faculty of Science and Head of the School of Psychological Science at UWA, Professor Bucks brings a distinguished academic and scientific background to the Raine Study.

She sits on the board of the Australian Psychology Accreditation Council, and in 2018 was made a Fellow of the Association for Psychological Science for her contribution to the field.



Professor Romola Bucks



Winners of the 2020 Australian of the Year Awards announced

NEWS.com.au - 25 Jan 2020

Professor John Newnham has been named the Senior Australian of the Year ... In 1989 he founded the Raine Study, the world's first and most ...

Awards and achievements - January 2020

Monday, 6 January 2020

The University of Western Australia has a continual roll call of awards, scholarships and prizes presented to staff and students.

To recognise these achievements, an article is published on the UWA NEWS page on the website and in UWA Focus on the first week of every month. If you know of great awards or achievements across the University please email uwa@news@uwa.edu.au

Name: Professor Paul Partzel, Faculty of Health and Medical Sciences

Achievement: Professor Paul Partzel, Chair of Radiology at UWA and Royal Perth Hospital has recently returned from Lima, Peru, after being awarded an honorary membership of the Peruvian Society of Radiology at the International Course on Neuroradiology. Professor Partzel has a history of working in the region to promote the Peruvian radiological community.

Name: Dr Anthony Duckworth-Smith, School of Design, Faculty of Arts, Business, Law and Education

Achievement: AUDRC Research Fellow Anthony Duckworth-Smith and a team from AUDRC, City of Fremantle and Creating Communities have received the award for 'Best Planning Ideas - Small Project' at the Planning Institute of Australia 2019 WA Awards for Planning Excellence for their project 'The Fireo Alternative: big thinking about small housing'.

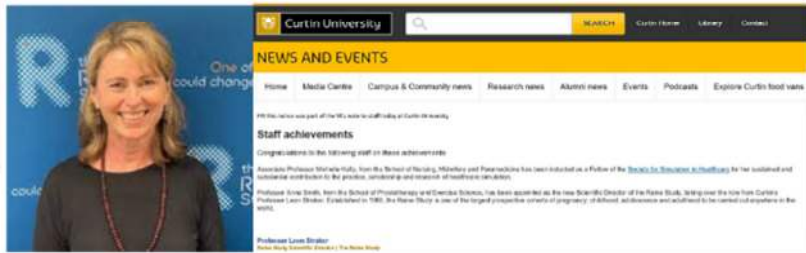
Name: UWA Raine Study, Faculty of Health and Medical Sciences

Achievement: UWA's Raine Study research initiative was presented with a Lotterywest cheque for \$160,209 by The Hon. Alanna Clofesy MLC. The Lotterywest grant is to support and enhance access to research findings delivered by the Raine Study to improve health and well-being outcomes for the WA community.

Achievement: Dr Maria Ignatieva has received the National Award in Landscape Architecture, awarded by the Association of Landscape Architects of Russia. The Russian National Award for Landscape Architecture was established in 2010 and recognises outstanding professional achievements and contributions to the field.

Name: Daniel Lightowler, Faculty of Health and Medical Sciences

Achievement: Daniel Lightowler has received the National Award in Landscape Architecture, awarded by the Association of Landscape Architects of Russia. The Russian National Award for Landscape Architecture was established in 2010 and recognises outstanding professional achievements and contributions to the field.





Content Created by the Raine Study

Social media presence grows

In 2020, the Raine Study continued to grow and evolve its social media presence across its various platforms. With changes in personnel and resourcing, we explored key data from our social media efforts to determine on which platforms we would focus our somewhat limited resources, taking into account the Raine Study's overall strategic objectives and most important audiences.

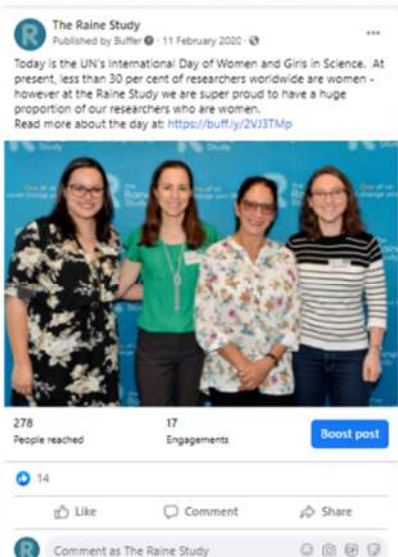
With that in mind, the decision was made to step away from our Instagram account due to a lack of visually engaging content or the resources to create it. We decided to focus instead on building our LinkedIn presence, to engage more specifically with institutional stakeholders, government bodies and other research institutions.

We retained our focus on Facebook as an excellent vehicle for engaging with our participants (more so Gen1 than Gen2), and determined that we would deploy a new strategy on Twitter for engaging with researchers once new Director Professor Romola Bucks' tenure was underway in early 2021.

The most popular stories across all platforms were those focused on the people of the Raine Study, whether that be staff, participants or researchers – a fitting testimony to our mission of changing lives.

Summary of the Raine Study's year on year performance on social media in 2020:

- Facebook: Increased followers by 6% to 914
- LinkedIn: 200% increase in followers to 97
- Twitter: Increased followers from 295 to 341 (15% increase)
- Instagram: Had increased following by 3% through until September 2020



Newsletters

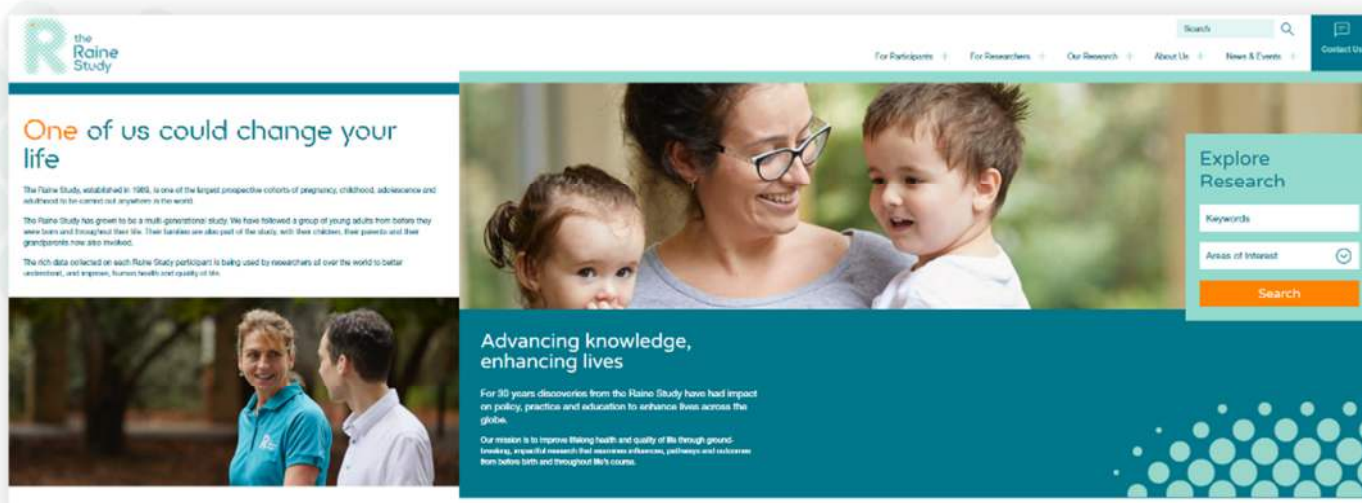
Newsletters, or email marketing, is another strategy for staying connected with participants and researchers. Newsletters were sent to these audiences 3x in 2020, in February, June and November. Open rates are above industry average. We are continuing to review our newsletters to ensure that the call to action remains strong e.g. for participants – update your information to enable contact tracing; for researchers – remember to cite and reference the Raine Study when promoting publications or presentations.

Website

The Raine Study's website continues to be an important focus of marketing effort, not just on the News page but as a resource for researchers looking to access further information about working with the Raine Study and areas of focus.

Over the course of 2020 we grew the number of monthly site sessions (the number of times users visited the Raine Study's website) to a high point of 4,554 in October, mainly related to the Annual Scientific Meeting on 30 October. October also saw us peak at 8,400 page views, which was 17% higher than any other month.

On average across the year, 65% of users are coming to the Raine Study website through organic search and around 25% through direct traffic (those who type the Raine Study's website address directly into a search engine). While this is good news from the perspective that users are seeking information about the Raine Study, more can be done to increase our searchability online. In late 2020, we commenced planning a series of upgrades to our website to help in this regard.





Appendix: Publications List 2020

- * Appannah G, Murray K, Trapp G, Dymock M, Oddy WH, Ambrosini GL. Dietary pattern trajectories across adolescence and early adulthood and their associations with childhood and parental factors. *Am J Clin Nutr.* 2020.
- Ayonrinde OT, Ayonrinde OA, Adams LA, Sanfilippo FM, TA OS, Robinson M, et al. The relationship between abdominal pain and emotional wellbeing in children and adolescents in the Raine Study. *Sci Rep.* 2020;10(1):1646.
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- * Beynon AM, Hebert JJ, Leboeuf-Yde C, Beales DJ, Jacques A, Walker BF. Early life chronic inflammatory conditions predict low back pain in adolescence and young adulthood. *Eur J Pain.* 2020.
- * Boutrus M, Gilani Z, Maybery MT, Alvares GA, Tan DW, Eastwood PR, et al. Brief Report: Facial Asymmetry and Autistic-Like Traits in the General Population. *J Autism Dev Disord.* 2020.
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- Dyer KIC, Sanfilippo PG, White SW, Guggenheim JA, Hammond CJ, Newnham JP, et al. Associations Between Fetal Growth Trajectories and the Development of Myopia by 20 Years of Age. *Invest Ophthalmol Vis Sci.* 2020;61(14):26.
- Eastwood P, Gilani SZ, McArdle N, Hillman D, Walsh J, Maddison K, et al. Predicting sleep apnea from three-dimensional face photography. *J Clin Sleep Med.* 2020;16(4):493-502.
- English MCW, Gignac GE, Visser TAW, Whitehouse AJO, Maybery MT. A comprehensive psychometric analysis of autism-spectrum quotient factor models using two large samples: Model recommendations and the influence of divergent traits on total-scale scores. *Autism Res.* 2020;13(1):45-60.

- Fan Q, Pozarickij A, Tan NYQ, Guo X, Verhoeven VJM, Vitart V, et al. Genome-wide association meta-analysis of corneal curvature identifies novel loci and shared genetic influences across axial length and refractive error. *Commun Biol.* 2020;3(1):133.
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