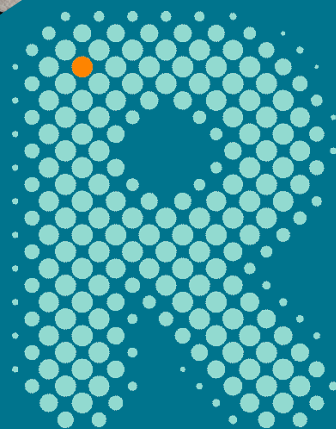


2021 ANNUAL ACTIVITY REPORT



the
Rainie
Study



Researchers, participants, UJV partners, dignitaries and staff come together at the Raines Study's 2021 Annual Scientific Meeting



				
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MESSAGE FROM OUR CHAIR

Looking back on 2021, I am immensely proud of all that the Raine Study has achieved under the new and extremely capable leadership team of Professor Romola Bucks and Associate Professor Rebecca Glauert. Indeed, as I start to review all that has been achieved under globally trying circumstances, it is incredible to think that the Directors have worked together for only a year – but what a 12-months it has been.

Both have brought distinct skills and attributes to their new roles – Romola as a powerful leader of people, Rebecca as a highly respected epidemiologist and expert in data linkage and scientific management – and they have developed a strong working relationship which will only benefit the Raine Study in the years to come.



L-R: Romola Bucks, Jan Stewart, Rebecca Glauert

Under their leadership, highlights for the Raine Study in 2021 include:

- The speed of progress they have made in defining the challenges facing the Raine Study, and the innovative way they have sought to address these challenges;
- A successful grant application to Lotterywest to fund the proposed WA Cohort Data Portal scoping study by convincingly demonstrating that data collaboration is key to delivering improved social and health outcomes for all West Australians;
- Securing landmark funding from the Stan Perron Charitable Foundation to safeguard the Raine Study's future. This grant will enable investment in strategic planning capacity, and in the capacity of our specialist staff required to improve and enhance access to the Raine Study's extensive biosamples and health data;
- Renewal of the Unincorporated Joint Venture agreement for the next five years, a very important step for the future of the Raine Study.



I would like to express our gratitude to Lotterywest and to the Stan Perron Foundation for their support as well as our longstanding partner for whom the study is named, the Raine Medical Research Foundation, for their continued support of the Raine Study since 1989.



I'd also like to thank and acknowledge the contributions of all the members of the Board of the UJV – our participant representatives William Aitken (Generation 2) and Martin Becker (Generation 1), Professor Tim Colmer, succeeded recently by Professor Anna Nowak, from the University of Western Australia, Professor Gary Allison from Curtin University, Professor John Olynyk from Edith Cowan University, Professor David Morrison from Murdoch University, Professor Gervase Chaney from the University of Notre Dame Australia, Professor Catherine Elliott from the Telethon Kids Institute, and Deborah Attard Portughes from the Women and Infants Research Foundation.

For our research and institutional partners, the last two years of pandemic conditions have not been easy, and we are grateful for their renewed and ongoing commitment.

We are grateful to our Patron, the Honourable Kim Beazley AC, Governor of Western Australia for his continuing support. We wish him well as he completes his term in 2022 and look forward to continuing this important vice-regal patronage with his successor, WA Police Commissioner Chris Dawson.

Lastly, I extend my thanks to the Directors Professor Romola Bucks and Associate Professor Rebecca Glauert for their leadership, Operations Manager Aggie Bouckley, Scientific Manager Dr Juliana Zabatiero, Data and Biosamples Manager Alex D'Vaux, Follow-Up Manager Diane Wood, Board Secretary Heather Campbell for her invaluable support to the UJV Board, and the entire team of the Raine Study for their dedication and hard work in the past year.

Most of all, I thank our four generations of participants. Without you, there is no Raine Study.

Jan Stewart
PSM, BA, MSW. HonDLitt.WAust, FAIM, GAICD
Chair, The Raine Study
May 2022





DIRECTORS' REPORT

According to the Ancient Greek philosopher Heraclitus, the only constant in life is change. That much is true of 2021, and the Raine Study team demonstrated yet again how flexible and adaptable they are in the face of change.

After the obvious challenges of 2020 – not only the onset of a global pandemic but also the departure of the Raine Study's long-serving leadership team of Professor Peter Eastwood (Director) and Professor Leon Straker (Scientific Director) – 2021 was always going to be a pivotal year for the Raine Study.

As the new Director (Professor Romola Bucks), my first task was the recruitment and appointment of the Raine Study's new Scientific Director. We were delighted to welcome Associate Professor Rebecca Glauert from Telethon Kids Institute into this role. An important start of the transition to the new leadership team was a team building session offsite at which the entire staff came together to identify our common goals and challenges for the year ahead.



2021 was also a time of transition and consolidation for the Raine Study's governance which marked the end of the first 5-year agreement signed by our Unincorporated Joint Venture partners in 2017.

All partners have committed to a new Joint Venture Agreement, to continue on from the first, for the period 2022-2027. We were also immensely fortunate that our inaugural Chair of the UJV Board Dr Jan Stewart agreed to continue in that role. As directors, we are most grateful for her insight, unwavering support, and shrewd guidance.



From the perspective of our future sustainability, 2021 was a year of reckoning for the Raine Study. Financially, we were challenged to identify new sources of funding in a world where our usual sources of research funding were increasingly diverted to address the immediate and near-term impacts of the COVID-19 pandemic. We were also forced to deal with the unanticipated loss of a significant percentage of the Raine Study's historical biosamples due to a freezer malfunction. Fortunately, none of the data collected from these samples were lost.

We responded to both sets of challenges by pivoting to work smarter and better. We successfully applied for over \$1 million AUD in new funding from the Stan Perron Charitable Foundation towards the work of the Raine Study and from Lotterywest. The Lotterywest funding will support our new strategic focus on data linkage in partnership with our fellow Western Australian cohort studies the Busselton Health Study and ORIGINS Project.

We also successfully completed the case, begun by Professor Peter Eastwood, for a significant insurance claim on the freezer malfunction. The funds received from this claim are enabling us to plan for a 2-generation follow-up commencing in 2023. This is the first time we will be able to apply the same follow-up measures and tests to our Generation 1 and Generation 2 cohorts at the same time: a true milestone for the Raine Study.



From a science perspective, the Raine Study's research output continues to grow, with our researchers publishing 55 new papers in peer-reviewed journals across a large range of topics. These included publications in several new areas of research focus for the Raine Study, as well as consolidating our reputation in many of the research areas for which we are historically known.

This work clearly demonstrates the strength of the Raine Study's commitment to advancing knowledge across all stages of the human life course, and all aspects of health and wellbeing.

While we were disappointed that ultimately, we had to cancel the 30-year celebrations of the establishment of the Raine Study which we had had to postpone in 2020, our participant group responded well to this difficult decision.

We promised that we would reward their 30 years of commitment to us by finding new ways to acknowledge and celebrate their support. We did this through public award submissions on their behalf (for Western Australian and Australian of the Year Awards), commissioning of a 30-year celebration book, increasing the number of participants we were able to welcome to the Raine Study's Community Advisory Committee, and showcasing their involvement at our Annual Scientific Meeting.



We reciprocate their commitment to us by investing in new ways of engaging with participants such as the Visual Consent project: a project designed to develop a more accessible information sheet and consent form for our follow-up.



So, whilst 2021 was indeed a year of change at the Raine Study, it was also a year of resilience, new beginnings, and the seizing of new opportunities.

On behalf of the entire Raine Study team, we are delighted to present the Raine Study's 2021 Annual Activity Report. We would like to acknowledge and thank our participants, our researchers, and our funders, particularly the University of Western Australia, the Raine Medical Research Foundation (our first funding partner), Lotterywest, the Stan Perron Charitable Foundation, and the National Health and Medical Research Council (NHMRC), for their support of the Raine Study.



We thank our UJV Board partners, the Women's and Infants Research Foundation, UWA, Curtin University, Telethon Kids Institute, Edith Cowan University, Murdoch University, the University of Notre Dame, our two participant representatives, and our Institutional Associate Members: Flinders University and the University of Newcastle (NSW), for their continued support of the Raine Study. With their support, we look forward to continued success in 2022.

Professor Romola S Bucks
Director, The Raine Study

Associate Professor Rebecca Glauert
Scientific Director, The Raine Study





PROGRESS AGAINST STRATEGIC PLAN

1. Build Organisational Capacity

Welcomed new/ongoing leadership.

- Welcomed new Scientific Director, Associate Professor Rebecca Glauert to the Raine Study.
- Re-appointed UJV Board Chair, Dr Jan Stewart.

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.
- Completed EMCR Webinar and Workshop in partnership with UWA DVCR and researchers from UWA, Curtin University and Telethon Kids Institute.
- Worked with the UJV Board members to develop a Joint Venture agreement to continue on from the current agreement from 2022-2027.

Strengthened staff capacity

- Provided professional development opportunities to staff.
- Recruited highly skilled professionals into vacant positions including Scientific Director, Scientific Support Officer, Generations Follow-up Research Administrative Assistant and Data Officers.
- Recruitment of 4 communications interns (July-November) to strengthen our capacity to showcase institutional researcher successes and increase researcher engagement.

Strengthened committee functioning

- Professional Development provided for new RSCAC Chair and Deputy Chair by the Consumer and Community Involvement Program (CCIP).
- Implemented updated SRC review processes for new project applications.
- Facilitated regular and consistent meetings of Committees - Scientific Management Committee (10) 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

- Engaged a new Research Project Administrative Assistant to conduct contact tracing for the new Generations Follow-up.
- Distributed three newsletters (February, June, November) to Gen1 and Gen2 participants.
- Used social media platforms, video conferencing, newsletters and website content 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 2021. Four meetings were held in-person with the option of joining online.

Maintained adequate facilities

- New conference room facilities were installed.

Built IT capacity

- ISA Technologies provided ongoing IT support for ROSSv2.0.
- IT equipment upgrades commenced for staff members and laptops were provided for those who require them.
- All staff were provided with the IT requirements to work from home if required.

2. Create financial sustainability

- Developed new Joint Venture Agreement including financial commitments from our partner institutions.



- Facilitated grant or fellowship applications to local, national, and international grant schemes. Sixteen (16) grant applications were submitted in 2021, of which 2 were successful and we await the outcome of a further 2 in 2022.

3. Build science capacity and culture

Increased participant engagement in science

- Increased cohort involvement with participants engaged in the ground-breaking new Visual Consent (VisCon) project to develop new Information and Consent Forms.
- Communications interns worked on identifying publication findings to highlight and share with participants and translate into language that is more compelling for the general public and participants to read.

Developed Special Interest Groups

- Held Webinar introducing the Raine Study to researchers.
- Held two workshops for Early and Mid-career researchers and clinical researchers, to engage with the Raine Study, aiding them to develop their project ideas to use data and/or biosamples.
- Encouraged all researchers to update their SIG interests via their ROSS accounts.

Developed resources

- Completed quality control on three recently completed follow-ups.
- Employed a biosamples specialist 1x day per week to provide advice and support for management of biosamples.
- Recruited a Records Digitisation Assistant for a short-term project to scan all consent forms, catalogue, label and archive documents.
- Added the Raine Study to the UWA Research Repository (Pure) to facilitate searches for research using Raine Study data.

Increased science activity

- 44 new projects were entered into the Raine Study's Online Submission System (ROSS)
- 101 new data access requests and 1 request for biosamples were made
- 64 new manuscripts were proposed, and 50 new manuscripts were submitted
- 337 amendments were made to existing projects
- 55 papers were published in peer-reviewed journals in 2021, resulting in a total of 649 published papers using the Raine Study data.

4. Enhance awareness and impact

- Director and Scientific Director held a number of meetings with key institutional stakeholders (current/prospective) to raise the Raine Study profile.
- Strengthening partnerships with Origins and Busselton Health Study through WA Cohort Portal.
- Science interns assisted with identifying and communicating the impact of the Raine Study locally, nationally, and internationally.
- Engaged with the Communications teams from UJV partners to ensure more prominent promotion of the Raine Study impact stories.
- Directors and Board Chair met with the Governor and patron of the Raine Study, the Honourable Kim Beazley at Government House.

2022 PRIORITIES

Ongoing organisational development

- Planning for the sustainability of the Raine Study in 2022 and beyond.

Ongoing data collection

Planning for the Generations follow-up commencing in 2023.



ABOUT THE RAINE STUDY



Established in 1989, the Raine Study is one of the world's longest-running pregnancy and birth cohort studies and the most successful and extensive survey of health from the womb to adulthood.



4 GENERATIONS

Gen0	Gen1	Gen2	Gen3
Grandmothers	2,900 pregnant women & fathers	2,868 children	500+ new babies



14
research areas

30,000

pieces of data per participant

30 million

pieces of genetic information per participant

600+

peer-reviewed journal articles published



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 Values

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

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

We are endlessly **curious**. We search for new discoveries that can improve human health and quality of life. This is what motivates us.

We know the only constant is **change**. We must keep reinventing ourselves and redefining the value we bring in order to stay ahead.



Multigenerational Value

The Raine Study is a longitudinal cohort study. It relies on the same group of genetically-related family members originally recruited between 1989 and 1991 to participate in each follow-up. The longer the same people continue to take part in the study, the more valuable their data become.

Based in Perth, 2,900 pregnant women (Gen1) were recruited to be part of the Raine Study between 1989 and 1991, giving birth to 2,868 children (Gen2, the initial focus of the Raine Study). Our Gen2 participants have now turned 30 and have taken part in a remarkable 17 follow-up studies since before they were born until now, each contributing over 30 million pieces of genetic data. Over 73% of our Gen2 participants are still actively involved in Raine Study assessments.

In addition to the original Gen1 and Gen2 participants, the Raine Study has recruited 109 grandmothers (Gen0) of the original Raine Study children and more than 500 babies (Gen3) born to our now adult Gen2 participants.



Life-Course Research

Hundreds of researchers in Australia and around the world use data collected and collated by the Raine Study to power breakthrough discoveries across all aspects of human health including cardiometabolic health, diet, education and work, physical activity, sleep health, reproductive health, respiratory health, hormones, immunology, mood and mental health, and more.

To date, over 600 peer-reviewed journal articles have been published based on Raine Study research data. Because of the Raine Study, the medical world has:

- Established the safety of ultrasounds and set the standard for routine prenatal ultrasound scanning worldwide;
- Identified genes associated with birthweight, lung function, language development, puberty and reproductive development;
- Discovered that children who were breastfed for four months or longer had a healthier weight, suffered less asthma and allergies and fewer behavioural problems into adolescence and beyond.

A Uniquely Collaborative Resource

The Raine Study is funded and managed as an Unincorporated Joint Venture between all five Western Australian-based universities as well as Telethon Kids Institute and the Women and Infants Research Foundation, with ongoing support from our original funding partner the Raine Medical Research Foundation. Visit rainestudy.org.au for further information.





GOVERNANCE

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

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, with 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. 2021 marked the completion of the original terms of the Joint Venture Agreement. All partners have committed to a new Joint Venture Agreement for the period 2022-2027.

UJV Board

The Raine Study UJV Board is comprised of representatives from each partner in the Unincorporated Joint Venture agreement, representatives of the Raine Study participant community (Generation 1 and Generation 2), and an independent Chair (Dr Jan Stewart).

Members are expected to attend 3-4 meetings per year, engage in the initiatives and the outcomes being pursued by the Raine Study, and advocate for the Raine Study in the broader community. The Board is supported by Heather Amos, Board Secretary.

In 2021, the members of the UJV Board were:

- Martin Becker (Gen1 Participant, The Raine Study)
- William Aitken (Gen2 Participant, The Raine Study)
- The University of Western Australia: Professor Tim Colmer¹
- Curtin University: Professor Garry Allison
- Edith Cowan University: Professor John Olynyk
- Murdoch University: Professor David Morrison
- The University of Notre Dame Australia: Professor Gervase Chaney
- Telethon Kids Institute: Professor Catherine Elliott
- Women and Infants Research Foundation: Deborah Attard-Portugues
- Professor Romola Bucks (Director, The Raine Study)
- Associate Professor Rebecca Glauert (Scientific Director, The Raine Study)
- Aggie Bouckley (Operations Manager, The Raine Study)

¹ Professor Tim Colmer was succeeded by Professor Anna Nowak in late 2021.



UJV Board Members 2021



Martin Becker
Generation 1 Participant



William Aiken
Generation 2 Participant



Professor Tim Colmer
The University of Western Australia



Professor Gary Allison
Curtin University



Professor John Olyynk
Edith Cowan University



Professor David Morrison
Munich University



Professor Carvosa Chaney
The University of Notre Dame Australia



Professor Catherine Elliott
Telethon Kids Institute



Deborah Atard
Portugues
Women & Infants Research Foundation



Professor Hamols Burkis
The Raine Study



Associate Professor Rebecca Clancy
The Raine Study



Aggie Bourkley
The Raine Study



ORGANISATION & PEOPLE

Patron

The Honourable Kim Beazley 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 ever since.

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 UJV Board since 2017.

Director

Professor Romola Bucks



The Director provides scientific and operational leadership to the Raine Study. They work 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 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

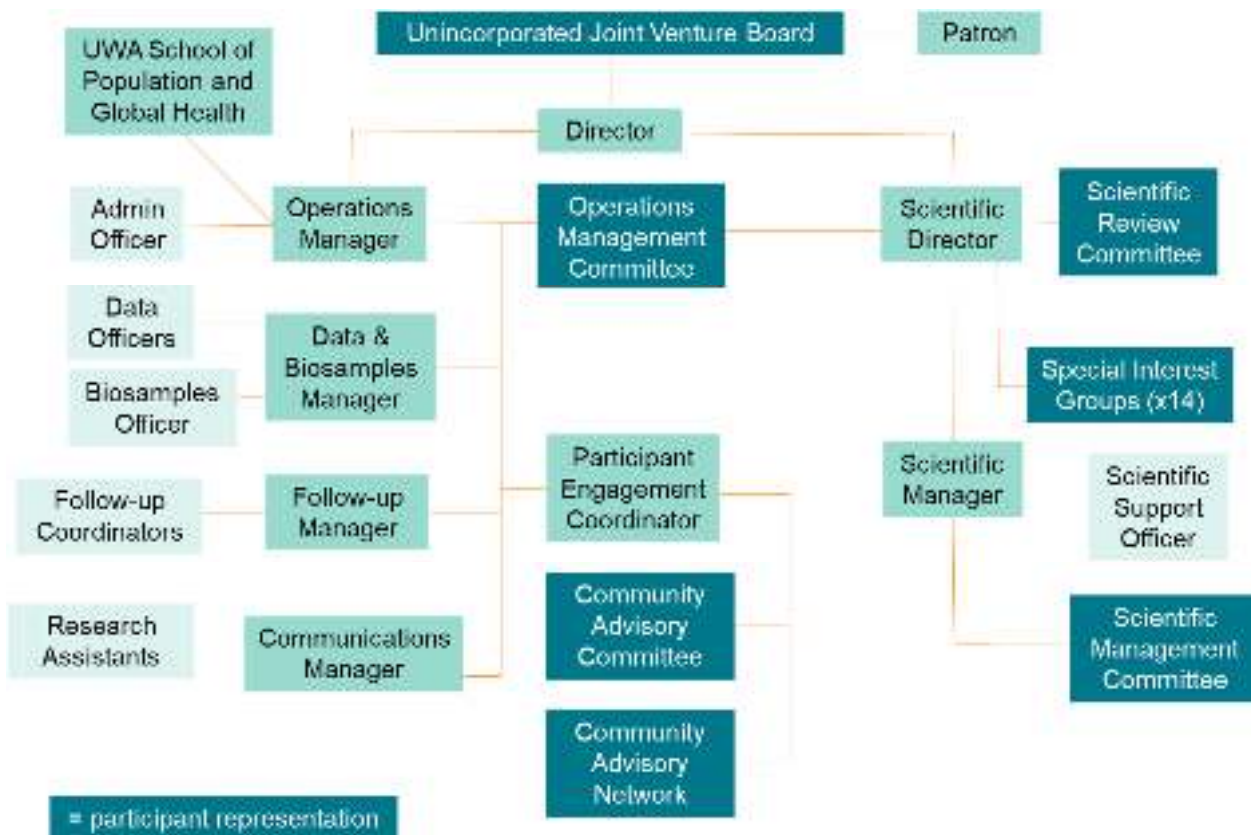
Associate Professor Rebecca Glauert



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.



Organisational Structure



Operational Staff

Operations Manager

Aggie Bouckley

The Operations Manager has responsibility for all operational matters including finance, human resources, corporate support, and oversight of operational issues related to cohort follow-ups, data and biosamples management, communications and participant engagement. The Operations Manager manages the efficient coordination of the Raine Study between the Host UWA School of Population and Global Health, university business partners, internal and external stakeholders and the joint venture partners. This is a 0.8FTE 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 responsible for the supervision of data officers. This is a 0.6FTE position.

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 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 2021 this position was 0.2FTE.

Communications Manager

Kate Rowlands

The Communications Manager is responsible for promoting the Raine Study externally via the development of overall brand strategy in support of corporate reputation. This is achieved through communications via the website and social media, newsletters, media relations and events targeting the Raine Study's participants, researchers, key stakeholders and the general public. The Communications Manager consults regularly and works closely with the Raine Study Directors, operations and research staff. In 2021, this was a 0.6FTE position.

Administrative Officer

Heather Amos (Campbell)

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 is a 0.8FTE position.

Project Officer (Biosamples Support)

Blagica Penova-Veselinovic

The Project Officer (Biosamples Support) contributes to the management activities of the Raine Study's biosamples, coordinates their curation and advises on their preparation and distribution. The Biosamples Officer contributes to developing procedures for the collection of new biosamples at new follow-ups. This position was established in September 2021 at 0.2FTE.

Data Officers

Dr Huong Le, John Langley, Harshdeep Sandhu, Alisha Davis, Brendan Smith, Katrina Ellis, Mei Ruu Kok, Nita Sodhi-Berry

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. In 2021, the total FTE was approx. 3.0FTE.

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 overseeing the recruitment of study participants and for the co-ordination of follow-up assessments including the protection of the study participants' interests, quality control of data collection, co-ordination, and scheduling of staff. In 2021 this position was 0.4FTE.

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 2021 this position was 0.2FTE.

Research Project Administration Assistant

Grace Cayley

The Research Project Administrative Assistant commenced with the Raine Study in November 2021 and supports the Raine Study's Participant Engagement Co-ordinator by contact tracing the participants via phone, text, email, and online, updating details on our database, ensuring we have the latest up to date contact details for the upcoming Generations follow-up. The role also supports the Communications Manager in social media communication to participants. This position is 1.0FTE.

Research Assistants

Sue Green, Beverley Hodgson

The Research Assistants are responsible for data collection, including physical assessment and questionnaire data, from Raine Study participants. In 2021 this included the collection of anthropometry measurements, echocardiogram, questionnaires and blood pressures. Research Assistants also have responsibility for the recruitment, booking and co-ordination of the study participants, and gaining research consent from them. In 2021, two Research Assistants worked on a casual and part-time basis approx. 0.75FTE.

Digitisation & Archiving Assistant

Melissa Wilson

The Digitisation Assistant completed the digitisation of consent forms, and labelled, catalogued, archived hardcopy medical and socioeconomic records, which were collected on the Raine Study participants over the lifetime of the Raine Study. This was a short-term casual position during the second half of 2021.

Scientific Staff

Science 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 2021 this position was 0.4FTE.

Project Officer (Scientific Support)

Monique Priston, Blagica Penova-Veselinovic

The Scientific Support Project 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. In 2021 this was a 0.4FTE position.

Scientific Programmer

Ray Smith

The Scientific Programmer develops applications that support the data collection, analysis, extraction and research collaboration functions of the Raine Study. They are responsible for advising, leading and developing the functional IT/IS requirements of the Raine Study team and the



Raine Study's end users, as well as developing the technical solutions to fulfil those requirements. In 2021 the Scientific Programmer completed the initial structure of the Raine Study database, an application portal concept for data extraction and a proof of concept for the data visualisation for external researchers. In 2021, this was a 0.6FTE position.

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 2021 were Professor Rebecca Glauert, Dr Juliana Zabatiero, Professor Romola Bucks, Alex D'Vauz, Diane Wood, Blagica Penova-Veselinovic 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 2021, 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 Romola Bucks, Professor Rebecca Glauert (Chair), Dr Juliana Zabatiero (Co-Chair), Blagica Penova-Veselinovic (Project Officer - Scientific Support), Rachel Wilkinson and Roland Kerr (Gen2 participants) and Dr Alison Kerr (Gen1 participant).

Special Interest Group Leaders Committee

Each special interest research group is led by 1-2 people representing a specific specialist area, selected and appointed by the Raine Study Directors. They work with the Raine Study team to maximise the utility and use 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 2021 were:

Dr Phillip Melton, Professor Craig Pennell, Dr Koya Ayonrinde, Professor Trevor Mori, Dr Peter Franklin, Dr Rachel Foong, Dr Melanie Walls, Professor Roger Hart, Professor Martha Hickey, Dr Rob Waller, Dr Darren Beales, 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 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 2021 were Roland Kerr (Chair), Martin Becker, William Aitken, Dr Alison



Kerr, Dr Ditzza Teng, Claire Adams (Deputy Chair), Cornel Scheibling, Charlotte Diaz, Rachael Avison, Janet Scott, Rosanna Candler (Secretary), Lori Fendel Sacks, Ruth Page, and Dion Saratsis, Stephan Elliot, Oliver Locke, Emma Woods, Aliesha Arbuthnot, Michele Keye, Genevieve Scott, Alasdair Hill, Rachel O'Sullivan, Margaret Croker, Amanda Aitken, Angela Knight, Rosemary Irvine and Jacqui Graham.

Additionally, Martin Becker and William Aitken represented the Community Advisory Committee on the UJV Board, Cornel Scheibling and Claire Adams on the Operations Management Committee, and Dr Alison Kerr and Roland Kerr 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 Manager, the Project Officer (Scientific Support), 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 2021 were Aggie Bouckley (Chair), Professor Romola Bucks, Professor Rebecca Glauert, Cornel Scheibling (Gen1 Participant), Claire Adams (Gen2 Participant), Dr Juliana Zabatiero, Diane Wood, Alex D'Vauz, Blagica Penova-Veselinovic, Kate Rowlands, Sue Green and Heather Amos as Secretary.

Students

Research Students

In 2021, there were 71 students working with the Raine Study, with the majority enrolled in Doctor of Philosophy (PhD) and Master's degrees (Figure 1).

Students Utilising the Raine Study Resources 2021

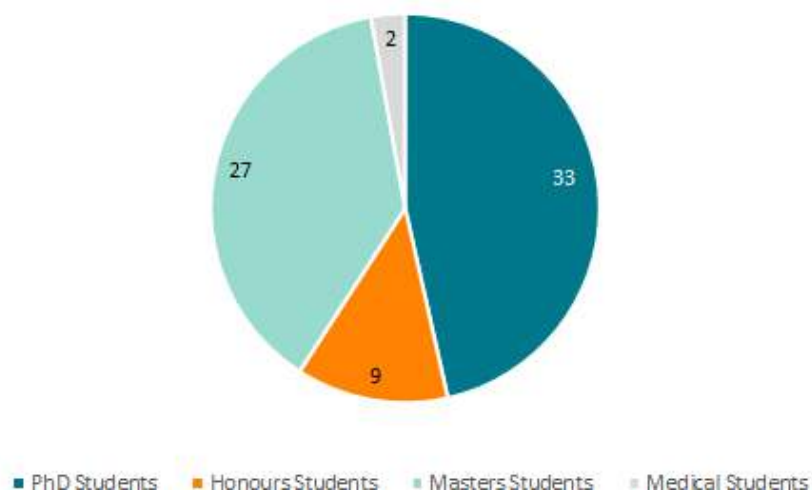


Figure 1. Students, by degree, who have utilised the Raine Study resources in 2021



Number of PhD Students Utilising the Raine Study Resources

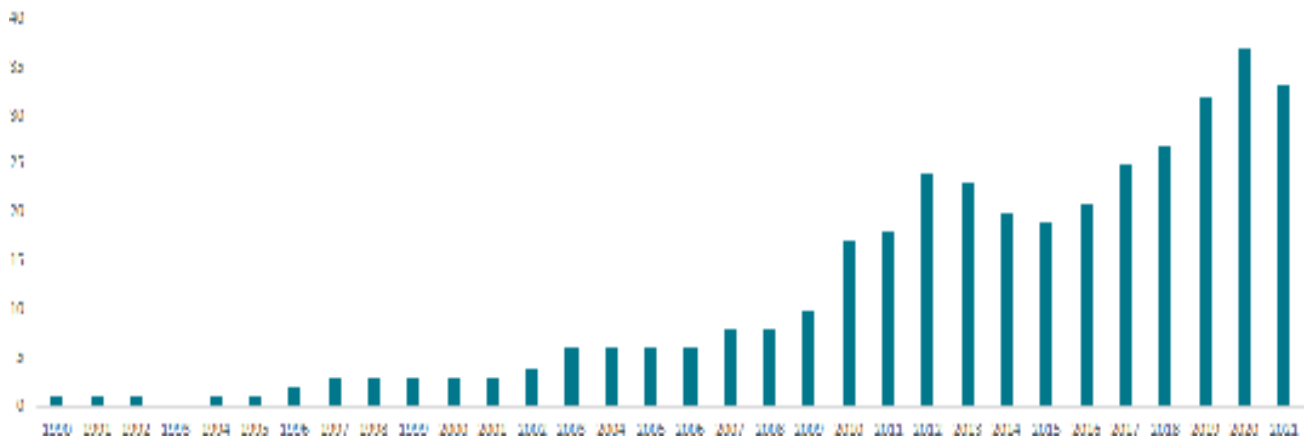


Figure 2. Number of students enrolled in a PhD program, who utilised the Raine Study resources, per year.

Interns

The Communications Manager worked with Raine Study staff and Directors to re-start the Raine Study's engagement with students, from interns and work placement students to research assistants, not just for the communications portfolio but across the Raine Study's scope of operations. Significant investment has been made to establish relationships with the University of Western Australia's Work Integrated Learning program as an initial source of prospective interns. New processes and procedures were developed to ensure that interns had a positive experience during their time at the Raine Study, with the ultimate aim of evolving them to become future ambassadors for the Raine Study across UWA and in their future roles.

From July-December 2021, the Raine Study hosted five interns from UWA's Science Communications and Science degree programs. Each completed an 80-hour internship placement, from induction training to end of placement presentation. Of these five students, Melissa Wilson has gone on to be hired on a casual basis by the Raine Study and in another role at UWA's Law School as a result of her involvement in the VisCon project.



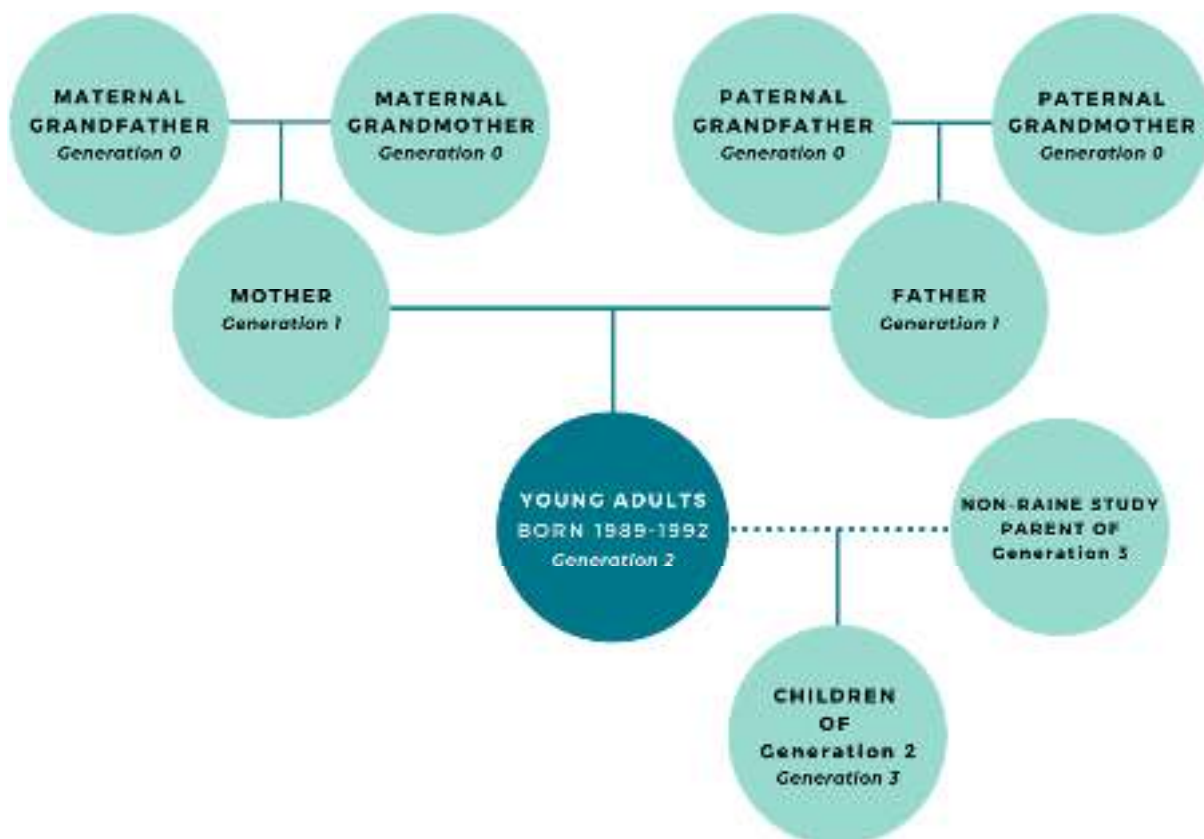


A further three interns from the UWA WIL program have been selected for the first half of the 2022 academic year. The Raine Study team hopes to be able to work with intern programs from across our UJV University partners.

PARTICIPANT ENGAGEMENT

The original Raine Study babies (Generation 2) have, on average, turned 31 years of age in 2021. From the original cohort of 2,868 babies born into the study, 2,096 remain registered as active participants, meaning that they have agreed to remain in the study and be contacted for future assessment.

Approximately 2,000 Raine Study parents (Generation 1) remain as active participants. To date, 783 offspring (Generation 3) have been born to and registered with the Raine Study by our Generation 2 participants. We have data on 109 grandparents (Generation 0) which we collected in 2019 during the Breast Density TiBS study. At the end of 2021, in preparation for the Generations follow-up in 2023, we commenced reviewing the contact details of all cohort members via the contact tracing skills of the newly-hired Research Project Administrative Assistant



The Raine Study participant community continues to provide a valuable community perspective for all Raine Study operational and scientific activities. In 2021, the Raine Study Community Advisory Committee completed a new round of recruitment and successfully increased its Generation 1 and Generation 2 membership to 24 local and interstate participant members. They are tasked with contributing to ideas for strategies 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.

Heart Function Follow-Up

The In 2021 we continued to collect heart ultrasound data via an echocardiogram on the Generation 2 cohort as part of the Gen2-28 year follow-up. By the end of 2021 we had completed 405 heart ultrasounds/echocardiograms. Data for this follow-up will continue to be collected until the end of June 2022, and we hope to reach a milestone of at least 500 participants.

We've enjoyed meeting many of our new Generation 3 participants (toddlers and babies) who have accompanied their Generation 2 participant parents to this round of follow-ups. Although they have not been part of the follow-up process at this time, we hope that this will change in the future.



Planning for the Generations Follow-Up (2023)

Since mid-2021, the Participant Engagement team has been working to plan and share details with participants about the new follow-up which will commence in 2023. It will be called the Generations follow-up and will involve both Generation 1 (parents of those born into the study) and Generation 2 (participants born into the study from 1989-1992).

The Generations follow-up will be historic for many reasons. Being able to collect consistent data and samples from two generations at the same time is something that we have never been able to do before. We believe that it will open many new avenues for future research using Raine Study data, which in turn will add significantly to the ongoing value of the Raine Study to researchers in Australia and around the world.



Calling all original Raine Study kids and parents!



The Visual Consent Project (VisCon)

In 2021, the Raine Study's Participant Engagement team commenced an initiative to simplify and streamline the existing process for securing informed participant consent to be involved in the Raine Study. Working in partnership with Professor Camilla Andersen from UWA's School of Law, the Visual Consent Project (VisCon) got underway with the goal of understanding how the existing Participant Consent and Participant Information forms used by the Raine Study at each follow-up could be combined and simplified, drawing on comic book contracting concepts.

The principles of VisCon are:

- Clear and transparent – so it is easily understood and has no “fine print”
- Engaging – so people actually read it and make an effort to understand it
- Convey the right spirit – so the ideals of the relationship are properly communicated
- Legally binding – with the input and approval of UWA's Ethics Committee which the Raine Study is bound by.

The project is ongoing through 2022, with the goal of being implemented for the Generations follow-up in 2023.



FUNDING FOR THE RAINE STUDY

The Raine Study Unincorporated Joint Venture (UJV) partners contribute annually to the core management costs of the Raine Study. The parties to the UJV agreement 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.

Flinders University and the University of Newcastle (NSW) are also financial contributors of the Raine Study. Flinders University was the first to become an Institutional Associate member of the Raine Study, with their membership commencing in 2019 for a period of 3 years. The University of Newcastle Australia became an Institutional Associate member a year later in 2020, also for a period of 3 years. Both universities made an annual financial contribution.

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

Grant Funding

Grant Applications 2020 (for 2021 funding)

Twelve (12) grant applications totalling AU\$7.64 million were prepared and submitted in 2020 for research projects to commence in 2021, of which four (4) were successful totalling over AU\$2.24 million.

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. 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.
3. Healthway Health Promotion Exploratory Research Grant (EoI). M Boyes, S Leitao, P Hasking, M Claessen, E Hill, T Tomlin, M Nayton. Promoting mental health in children with language and literacy difficulties. AU\$67,478.
4. Raine Priming Grant. E de Jong. Predicting asthma disease trajectories through systems-level analyses of immune memory. \$215,000.

Grant Applications 2021 (for 2022 funding)

Eighteen (18) grant or fellowship applications totalling almost AU\$8.88 million were prepared and submitted in 2021 for projects to commence in 2022, of which three (3) were successful totalling AU\$1,094,991. We await the outcome of a further one in 2022.

Funded

1. Spinnaker Health Research Foundation Seed Grant 2022. O Ayonrinde. Determining factors that underpin cardiovascular disease risk in young adults with fatty liver diagnosed during adolescence ten years earlier – a longitudinal cohort study. AU\$15,000.
2. Lotterywest. BMRI, Origins, The Raine Study: Development of sector initiative to provide better knowledge sharing and improve the health and wellbeing of the WA community. R Bucks, R Glauert, A James, J Hui, J Davis, D Silva, P Watt. \$206,600.
3. Stan Perron Charitable Foundation: Research People and Platforms 2021. R Bucks, R Glauert. Developing and safeguarding the Raine Study: Western Australia's largest longitudinal health study, from birth to adulthood. \$873,391.



RESEARCHER ACTIVITY

New applications to use the Raine Study data

In 2021 there were 44 new project applications, 102 new data access and biosample requests, 64 new manuscript proposals, and 50 new manuscripts submitted in ROSS.

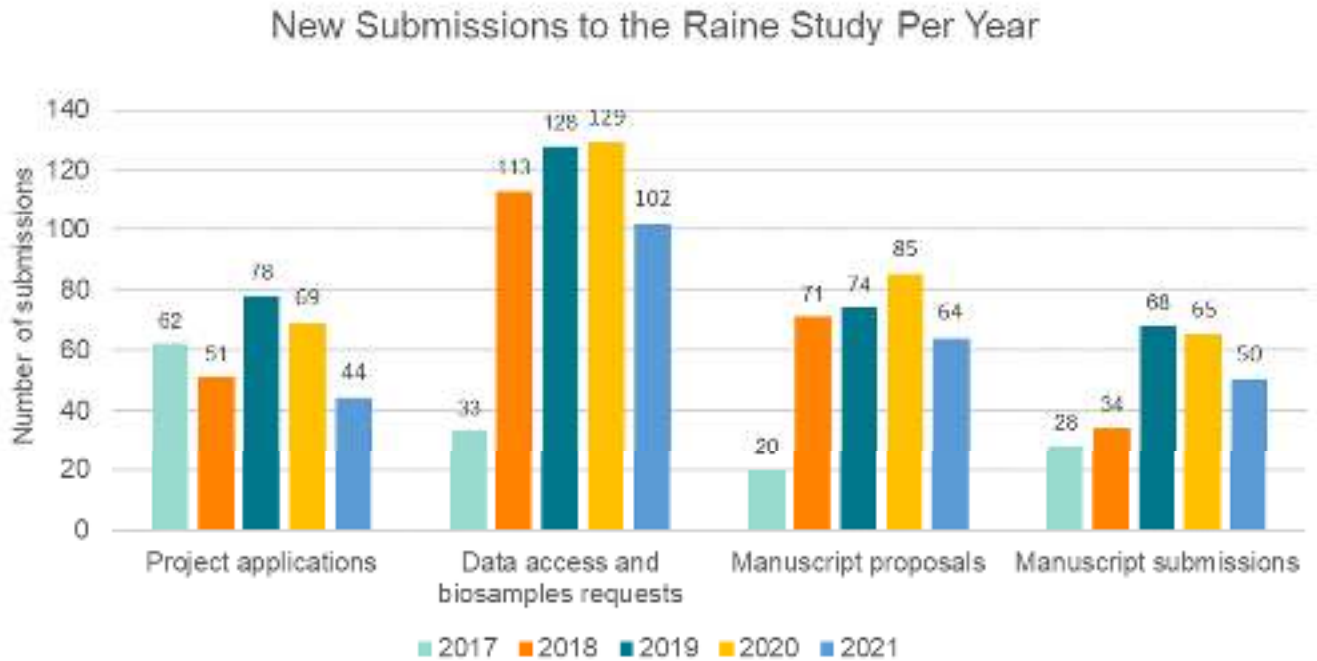


Figure 3. New Submissions to the Raine Study per year

Data collection during 2021

Grant Funded Activities Update 2021

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\$852,804.20. During 2021 we commenced collecting heart ultrasound data via an echocardiogram on the Generation 2 cohort as part of the Gen2-28 year follow-up. By the end of 2021 we had completed 405 heart ultrasounds/echocardiograms. This data collection will continue until the end of June 2022.

RESEARCH TRANSLATION, DISSEMINATION & IMPACT

Publications

In 2021, 55 peer-reviewed papers were published (includes two electronic publications from 2020 indexed in 2021; twelve electronic publications ahead of print in 2021, from which eight were indexed in 2022) bringing the total for the Raine Study to 649 (Figure 4), with over 94% of these in journals with impact factors of 2 or greater (Figure 5). The full list of publications during 2021 can be viewed in the Appendix.

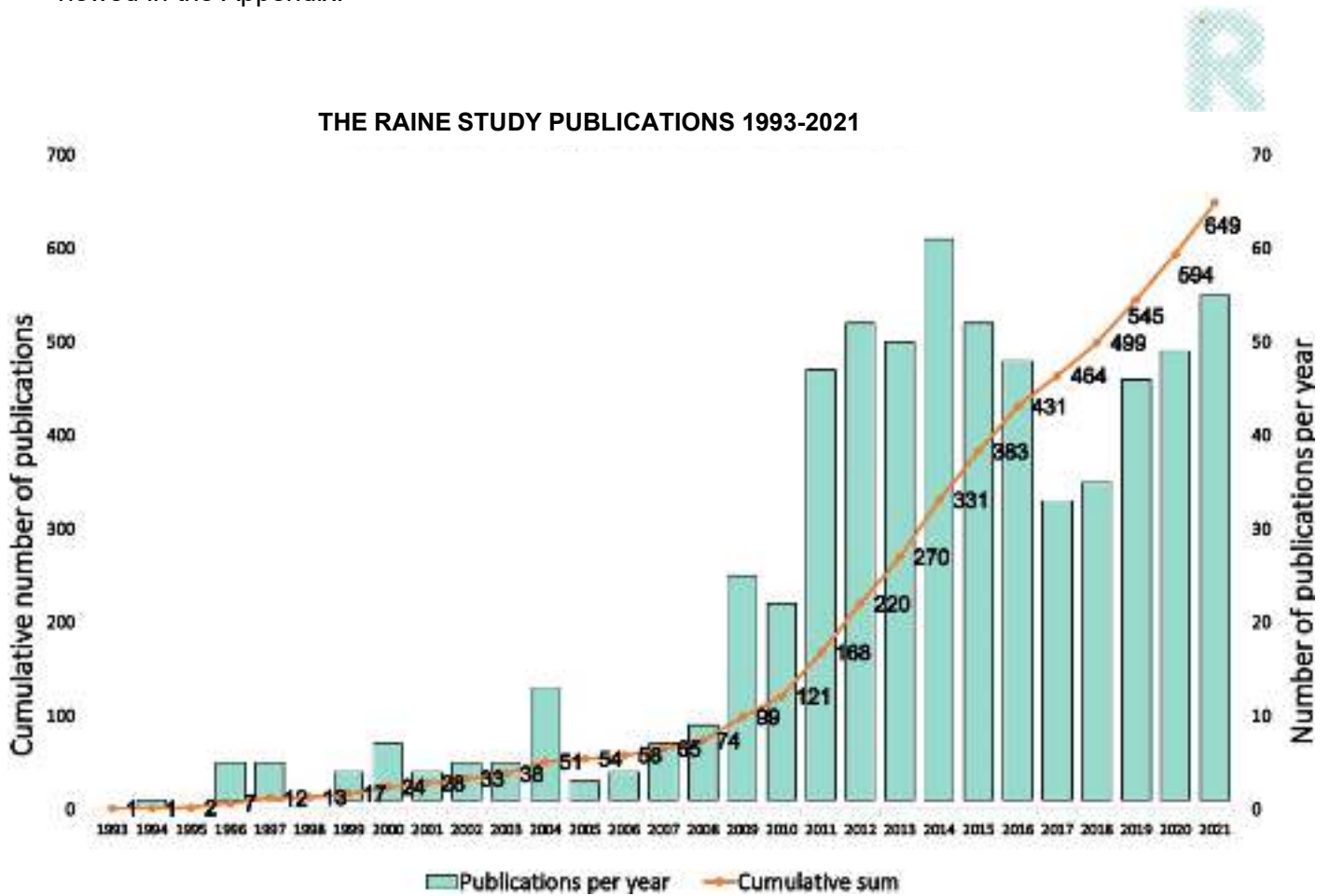


Figure 4. Number of the Raine Study publications by year (1993-2021)

THE RAINE STUDY PUBLICATIONS BY IMPACT FACTOR 1993-2021

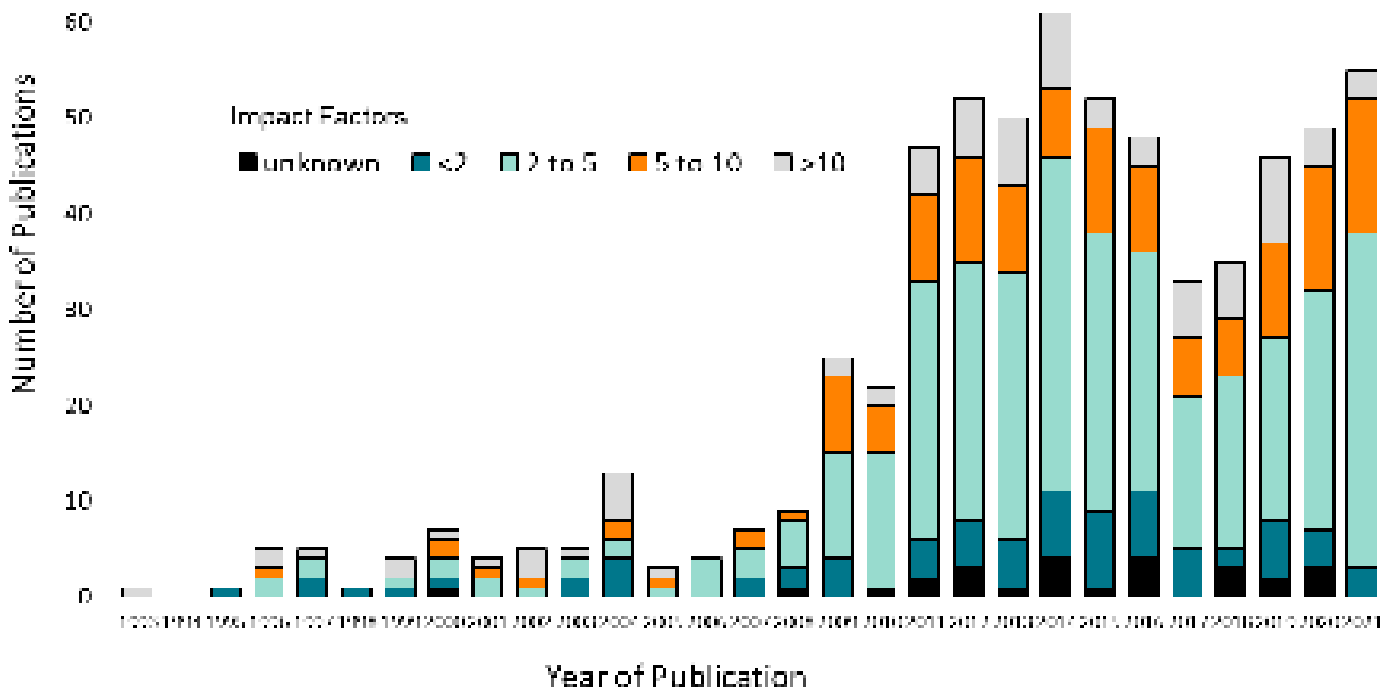


Figure 5. Number of the Raine Study publications by year and impact factors

THE RAINE STUDY 2021 PUBLICATIONS BY LOCAL INSTITUTION

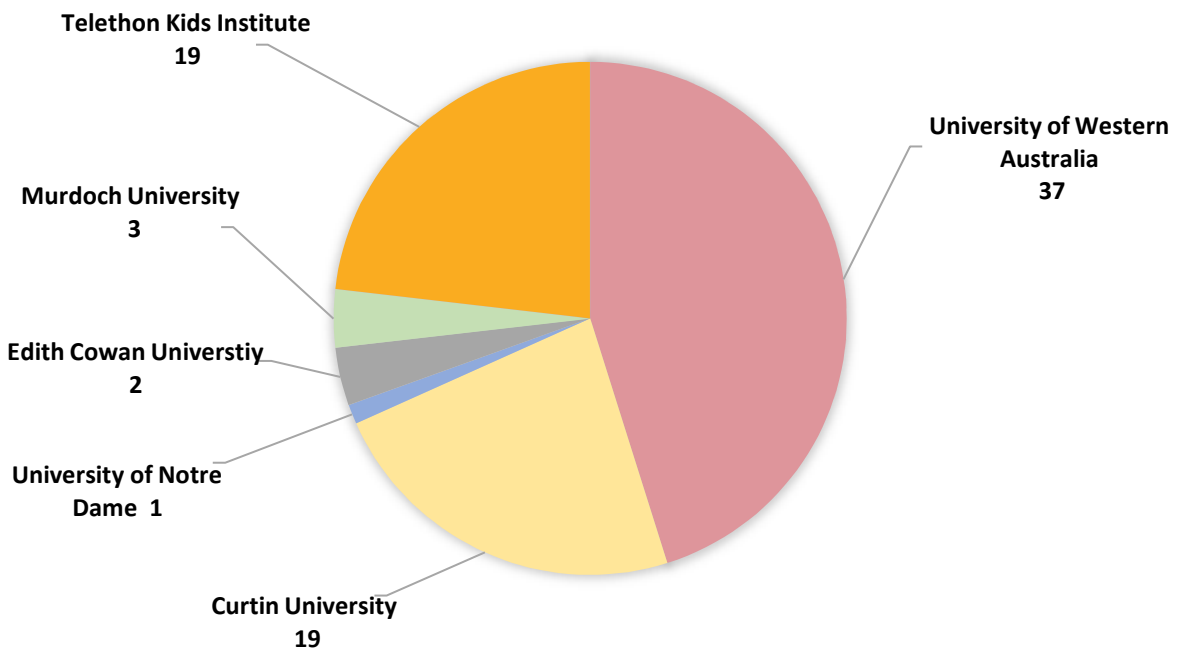


Figure 6. Number of the Raine Study publications in 2021 by local institution



COMMUNICATIONS & EXTERNAL ENGAGEMENT

Events

2021 Annual Scientific Meeting

Held as a blended event combining in-person and virtual attendance and presentations, the 2021 Annual Scientific Meeting marked the end of the Raine Study's 30-year anniversary celebrations and heralded the start of our new focus as we look ahead to the Raine Study's next 30 years. We challenged each of our presenters and attendees to address the question: what should the Raine Study's goals be as we set ourselves on the road towards another 30 years? With the Generations follow-up planned for 2023, new directors and a whole new generation of Raine Study participants being born, the 2021 ASM was an opportunity to come together as a community to share our many different perspectives on what the Raine Study's future might be, and to highlight the value that the Raine Study places on the contributions and ongoing engagement of its participant cohort.





In total, 122 guests registered to attend the event in person, along with another 45 attendees online. A welcome message was delivered via video by the Raine Study's Patron the Honourable Kim Beazley Governor of Western Australia, as the precursor to an in-person opening address by Generation 1 participant Amanda Aitken.

Keynote presentations were delivered by Professor Jeremy Nicholson, Director of the Australian National Phenome Centre, and Professor Fiona Wood, Director of the Royal Perth Hospital Burns Unit and the Western Australian Burns Unit, demonstrating the breadth of research areas to which Raine Study data might be applied.

Research presentations were delivered by eight student researchers, five early-career researchers and three mid-career researchers, and another five Raine Study researchers were involved as session chairs and panelists.

Presentations were also delivered by the Raine Study's collaborators for the VisCon project Professor Camilla Andersen (UWA School of Law), Peter Corner (Alternative Contracting), and Generation 2 participant Rachael Wilkinson. An additional three participants (Generation 1 Dr Alison Kerr, and Generation 2 Jessica Appleyard and Charlotte Diaz) were involved in a panel discussion on the future direction of the Raine Study.

Early and Mid-Career Researcher Presentations from the 2021 Annual Scientific Meeting

The following is the list of presentations made by mid and early career researchers using the Raine Study data at the 2021 Annual Scientific Meeting:

- Clustering of Rome IV-like irritable bowel syndrome, somatic pain and mental disorders in adolescents – a cross-sectional study. **Dr Koya Ayonrinde**, A/Prof Frank M Sanfilippo, Dr Oyediji A Ayonrinde, A/Prof Therese A O'Sullivan, A/Prof Leon A Adams, Prof Leon Straker, Prof John K Olynyk.
- Increased risk for otitis media infection in offspring following maternal prenatal stress exposure. **Dr Monique Robinson**, Prof David Burgner, A/Prof Ashleigh Lin, A/Prof Peter Jacoby, Prof John Newnham, Adj/Prof Robert Eikelboom, Prof Shyan Vijayasekaran, A/Prof Christopher Brennan-Jones.
- Incidence of myopia and change in ocular biometry between 20 and 28 years old. **Dr Samantha Lee**, Dr Gareth Lingham, Dr Paul Sanfilippo, Dr Seyhan Yazar, Prof David Mackey.
- Validation of open source actigraphy with in laboratory PSG in a large community population. **Kelly Sansom**, Prof Peter Eastwood, A/Prof Nigel McArdle, Dr Jennifer Walsh, Dr Kathleen Maddison, Clin Prof Bhajan Singh, Dr Amy Reynolds, A/Prof Joanne McVeigh, Dr Diego Mazzotti.
- Prenatal Tobacco Smoking and the Risk of Conduct Disorder Symptoms in offspring: Evidence from the Raine Study. **Bereket Duko**, Prof Gavin Pereira, Dr Robert Tait, Dr Kim Bett, Prof John Newnham, Prof Rosa Alati.
- Evaluating the distribution of foveal avascular zone area in a healthy, young population. **Qiang Li**, Dr Jason Charng, Prof David Mackey, A/Prof Fred Chen, Dr Peijun Gong, Hao Ho.
- What is the prevalence of idiopathic scoliosis, and do BMI, body image or back pain differ in those with idiopathic scoliosis? **Phoebe Ng**, A/Prof Kylie Tucker, Maree Izatt, Prof Leon Straker, Dr Jennepher Downs, Dr Andrew Claus.
- Developmental Sleep Trajectories and Adolescent Epigenetic Age Acceleration: A Prospective Cohort Study. **David Balfour**, Dr Phillip E. Melton, A/Prof Joanne A. McVeigh, A/Prof Rae-Chi Huang, Prof Peter Eastwood, Sian Wanstall, Dr Amy C. Reynolds, A/Prof Sarah Cohen-Woods.
- Scars of Socioeconomic Stress: Social Epigenetics. **Natasha Wood**, Dr Alexander O'Donnell, Dr Phillip Melton, Dr Richard Woodman, A/Prof Rae-Chi Huang; A/Prof Sarah Cohen-Woods.
- Fetal Growth Trajectories and their association with Adiposity and Inflammation in Young Adulthood. **Dr Ashish Yadav**, Prof Lawrie Beilin, Prof Trevor Mori, A/Prof Rae-Chi Huang, Philip Vlaskovsky, Prof John Newnham, Dr Scott White.



- Physical Activity and Healthy Bones in Young Adults. **Carrie-Anne Ng**, Dr David Scott, Dr Marc Sim, Dr Kun Zhu, Dr Aris Siafarikas, Dr Nicolas H Hart, Jocelyn Tan, Dr Paola Chivers.
- Flexible work fosters a flexible future work-self: the interplay of job autonomy and self-efficacy in the development of future work-self flexibility. **Dr Anupama Bharadwaj**, Prof Sharon Parker, A/Prof Patrick Dunlop.
- The relationship between fetal growth and retinal nerve fibre layer thickness in a cohort of young adults. Dr Katie Dyer, Dr Paul Sanfilippo, Dr Seyhan Yazar, Prof Jamie Craig, Prof Alex Hewitt, Prof John Newnham, Dr Samantha Lee, Prof David Mackey.
- 3D craniofacial analysis: applications in health. Dr Syed Zulqarnain Gilani, Prof Peter Eastwood, Dr Nigel McArdle, Clin/Prof David Hillman, Dr Jennifer Walsh, Dr Kathleen Maddison, Dr Mithran Goonewardene, Prof Ajmal Mian, Dr Maryam Boutrus, Prof Murray T. Maybery, Dr Gail A. Alvares, Dr Diana Weiting Tan, Prof Andrew J. O. Whitehouse.
- The relationship between foetal head circumference growth trajectories and nonalcoholic fatty liver disease in adolescents. **Dr Jeffrey Junhua Lee**, Dr Ashish Yadav, Prof Trevor Mori, A/Prof Rae-Chi Huang, A/Prof Leon Adams, Prof Lawrence Beilin, Dr Elizabeth McKinnon, Prof John Olynyk, Prof Craig Pennell, Dr Oyekoya Ayonrinde.
- Evidence that Infant and Early Childhood Developmental Impairments are associated with Hallucinatory Experiences: Results from a Large, Population-Based Cohort Study. **Dr Eleanor Carey**, Dr Colm Healy, Dr Yael Perry, Dr Diane Gillan, Prof Andrew Whitehouse, Prof Mary Cannon.

Early & Mid-Career Researcher Workshops

As part of its overall business goal of developing organisational capacity, increasing science capacity and overall awareness, the Raine Study undertook a number of initiatives to engage early and mid-career and clinical researchers who had not previously worked with the Raine Study. An online webinar and a Grand Round at Fiona Stanley Hospital were followed by two separate workshops were hosted, one in partnership with UWA and the other with the South Metropolitan Health Service at Fiona Stanley Hospital.



The goal was to educate new researchers about the breadth of data collected on each Raine Study cohort participant and how they can access the data for their own research. Attendees also participated in small groups to develop a research proposal and were provided the opportunity to work with Raine Study staff and experienced Raine Study researchers to refine their proposal.

Over 50 people attended the Grand Round at Fiona Stanley Hospital and 108 researchers registered for a preliminary webinar in advance of the workshops, and 34 researchers attended the



workshops in June and December. Significant interest and awareness were generated. The Raine Study's Scientific Management team continues to track new research proposals which entered in the Raine Study's Online Submission System (ROSS) because of these workshops.

Other Presentations in 2021 – National & International Events

The following is a snapshot of a range of presentations at other local, national and international events by researchers using the Raine Study data during 2021:

Prevalence and Modifiable Risk Factors for Hearing Loss and Tinnitus in Western Australian Young Adults

Nakano K.

Presented to the School of Biomedical Sciences, UWA Honours Presentations, 4 November 2021.

The association between different trajectories of low back pain and degenerative imaging findings in young adults from the Raine Study

Anne Smith, Mark Hancock, Susan O'Hanlon, Michael Krieser Peter O'Sullivan, Flavia Cicuttini, Leon Straker, Brendan Adler, Yuanyuan Wang, Jaro Karpinnen, Dino Samartzis, Darren Beales, Pieter Coenen, **Peter Kent**.

Presented at the 2021 Back & Neck Pain Forum, Global Virtual Conference, 11 Nov 2021

Early-life day-care attendance and the risk for asthma in children: Results from a multi-cohort consortium

Foong RE, Carson J, Sly PD, Hall GL, Huang R-C.

Presented at the Thoracic Society of Australia and New Zealand Annual Scientific Meeting, 1-2 May 2021

Longitudinal measurements of physical activity, sedentary behaviour, and sleep during critical developmental life stages: Novel insights from the Raine study. McVeigh JA,

Eastwood P, Howie EK, Smith A, Straker L.

Keynote address at ICAMPAM 2021 Virtual International Conference, 23-24 June 2021.

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.

ENDO 2021 Virtual Annual Scientific Meeting 20–23 March 2021.

The association of testosterone in umbilical cord blood and systolic blood pressure in offspring in young adulthood. Le-Ha C, Beilin LJ, Burrows S, Keelan JA, Hickey M, Mori TA.

Joint Meeting of the European Society of Hypertension (ESH) and International Society of Hypertension (ISH), on-air 11-14 April, 2021.

Methods to rectify discrepancies with adult blood pressure guidelines. Larkins N, Mori T, Choong C, Schlaich M, Beilin L.

Joint Meeting of the European Society of Hypertension (ESH) and International Society of Hypertension (ISH), on-air 11-14 April, 2021.

Prenatal testosterone associates with blood pressure in young adults: A prospective cohort study. Le-Ha C, Beilin LJ, Burrows S, Keelan JA, Hickey M, Mori TA.

University of Western Australia, Medical School Research Day, 5 May 2021.

Markers of cardiometabolic health of adolescents conceived through assisted reproductive technologies (ART) appear reassuring. Wijs L, Doherty D, Keelan J, Burton P, Yovich J, Beilin L, Mori T, Huang R-C, Adams L, Olynyk J, Ayonrinde K, Penova-Veselinovic B, Hart R,

37th Annual Meeting of the European Society of Human Reproduction and Embryology, Virtual, 27-30 June 2021.



Adolescent non-alcoholic fatty liver disease and future serum glucose levels in adulthood: a 10-year cohort study. Lee A, **Mori TA**, **Ayonrinde K**, Olynyk J, **Beilin L**, Adams L. Gastroenterology Society of Australia Australian Gastroenterology Week, Brisbane, Queensland, Australia, 12-14 September 2021.

Gender differences in characteristics of adolescents with non-obese nonalcoholic fatty liver disease. Ayonrinde K, Melton P, Elsegood C, Adris N, Adams L, **Mori T**, **Beilin L**, Olynyk J. Digital Liver Cancer Summit 2021, The European Association for the Study of the Liver, Geneva, Switzerland, 16-17 September 2021.

Fetal growth trajectories and their association with obesity in young adulthood. Yadav A, **Beilin, LJ**, Huang RC, Vlaskovsky P, Newnham J, White S, **Mori TA**. Australian Public Health Conference 2021, Hybrid Conference, Canberra, ACT, 23-24 September 2021.

Fetal Growth Trajectories and their association with Adiposity & Inflammation in Young Adulthood. Yadav A, **Beilin, LJ**, Huang RC, Vlaskovsky P, Newnham J, White S, **Mori TA**. Raine Study 2021 Annual Scientific Meeting, Perth, Western Australia, 29 October 2021.

The relationship between foetal head circumference growth trajectories and nonalcoholic fatty liver disease in adolescents. Lee JL, Yadav A, **Mori T**, Adams LA, **Beilin LJ**, McKinnon E, Olynyk J, Pennell C, Huang R-C, Ayonrinde OT. Raine Study 2021 Annual Scientific Meeting, Perth, Western Australia, 29 October 2021.

Fetal Growth Trajectories and their association with Adiposity & Inflammation in Young Adulthood. Yadav A, **Beilin LJ**, Huang RC, Vlaskovsky P, Newnham J, White S, **Mori TA**. 2021 HBPRCA Virtual Annual Scientific Meeting, 8-10 December 2021.

Evaluation of barriers to the timely detection of primary aldosteronism: a survey of the general community in Australia. Lai J, Gwini SM, Chen G, Long K, Russell G, Schlaich M, Stowasser M, Young M, Fuller P, Wolley M, **Mori T**, Reid C, Yang J. 2021 HBPRCA Virtual Annual Scientific Meeting, 8-10 December 2021.

The early life influences on adult male reproduction – Invited plenary presentation. **Hart, R.** European Society of Human Reproduction and Embryology, Paris 2021.

Endocrine disrupting agents in pregnancy and their implications for fertility. **Hart, R.** RANZCOG Annual Scientific Meeting, Hobart meeting 2021.

Finding out how genes and environment interact to cause myopia. Invited speaker: Mackey, D. Academy of Asia-Pacific Professor of Ophthalmology virtual congress. 4 December 2021.

Finding out how genes and environment interact to cause myopia. Invited speaker: Mackey, D. APAO 2021 Virtual Congress (APSEG Symposium: Prediction and Prevention of Myopia Progression). 7 September 2021.

Myopia: Genes, Sun, Electronic Devices and Eye-drops. Invited speaker: Mackey, D. Curtin Health Innovation Research Institute Seminar Series. 1 September 2021.

Future of Myopia. Invited speaker: Mackey, D. Future of Eye Care Symposium, RANZCO online. 17 May 2021

Conjunctival ultraviolet autofluorescence area is predictive of pterygium onset in young adults. Mackey, D. Abstract: Association for Research in Vision & Ophthalmology Annual Meeting (online virtual meeting) 2-6 May 2021.



Sun exposure and the eyes: harms and benefits. Invited speaker: Mackey, D.

Sun Exposure Summit (online Open Forum), Australian Skin and Skin Cancer Research Centre. 16 March 2021

Evaluating the distribution of foveal avascular zone area in a healthy, young population.

Qiang Li.

Raine Annual Scientific Meeting. 29 October 2021.

Choroidal thickness associations and longitudinal changes in young adults – findings from the Raine Study. Invited speaker: Lee, S.

Queensland University of Technology. 25 May 2021.

Correcting for axial length in macular thickness analyses. Lee S, Lingham G, Mackey DA, Chen FK, Franchina M, Blaszkowska M, Salisbury B, Niyazmand H, Yazar S, Alonso-Caneiro D. Poster presentation: Association for Research in Vision and Ophthalmology virtual 2021. 1–7 May 2021.

The relationship between fetal growth and retinal nerve fibre layer thickness measured in a cohort of young adults. Dyer K, Yazar S, Sanfilippo P, Newnham J, Craig JE, Hewitt AW, Mackey DA, Lee SY.

Oral presentation: Association for Research in Vision and Ophthalmology virtual 2021. 1–7 May 2021 for which Katie won an ARVO international travel grant

Online Communications

Social Media

Social media platforms are an important tool for the Raine Study's engagement with both participants and researchers as well as the broader community and stakeholders. In 2021, the Raine Study was focused on maintaining a corporate presence via its Facebook business page and LinkedIn, as well as with researchers via Twitter, and with participants and the broader community via Facebook. Some preliminary work was completed to reinstate the Raine Study's presence on Instagram as a precursor to 2022's participant contact-tracing efforts.





In 2021, social media engagement data increased across the board, thanks to dedicated resourcing (the Raine Study's communications interns) and assistance from partners to share content on their platforms.

Highlights include:

- Facebook: engagement increased by 37% throughout the year, with a high point of 1,380 unique visitors in October/November during promotion of the 2021 Annual Scientific Meeting.
- LinkedIn saw a steady increase in audience numbers and reach, with a maximum 1,100 post impressions during October, up from an average of 200 in January.
- A positive response to short-form video featuring staff, researchers, and participants.
- Focus on national and international health promotion days and weeks such as RUOK Day, Heart Week and National Science Week.
- Campaigns to source content in support of the 30 Year Celebration Book planned for online publication in 2022



A conversation could change a life.
One of us could change your life.





Website

As a result of staff and user feedback, and in preparation for the Generations follow-up in 2023, the Raine Study's Communications Manager undertook a design refresh for the website. The upgrade is scheduled to go live in the first half of 2022. This was the first style update to the website since 2018 and sees the introduction of a new lighter and brighter design palette, as well as a new menu, and focus on the Raine Study's engagement with Students.

Another important content development effort for the refreshed website will be a section dedicated to telling the story of the Raine Study's impact in plain language format. This has been a significant feature for our communications interns since July 2021 and is intended to help participants and general stakeholders appreciate the breadth of Raine Study research impact on health and wellbeing over the last 30 years.





Media Coverage

While the COVID-19 pandemic continued to be the focus of health and science coverage by the media, and with the ultimate cancellation of the Raine Study's 30th birthday celebration event as a result of pandemic restrictions, there were still significant placements for the Raine Study in 2021.

Nationally, Professor Roger Hart (Professor of Reproductive Medicine at UWA, Head of Fertility Services at King Edward Memorial Hospital and WIRF Research Fellow) and his team of researchers including the Raine Study's Scientific Officer Blagica Penova-Veselinovic, were featured in The West Australian newspaper and on Channel 7 news, for their breakthrough research into the longer-term health outcomes for children born via in-vitro fertilisation (IVF).

Internationally, Curtin University researcher Dr Karen Richards was interviewed by New Scientist magazine about her paper which showed that bad posture in teenagers is not a direct indicator of the risk of persistent neck pain in adults. Her original paper was published in the journal Physical Therapy in February 2021.

The West Australian

The Raine Study Helps Give IVF Kids A Clean Bill Of Health



IVF kids are given clean bill of health

Groundbreaking genetic study offers massive boost for children & parents

April 2021: New research from the [University of Western Australia \(UWA\)](#) and the [Women and Infants Research Foundation \(WIRF\)](#) using data from the Raine Study is being heralded as a major breakthrough in how we understand the longer-term health outcomes for children born via in vitro fertilisation (IVF).

Lead investigator [Professor Roger Hart](#), Professor of Reproductive Medicine at UWA, Head of Fertility Services at [King Edward Memorial Hospital](#) and WIRF Research Fellow, and his team of researchers including the Raine Study's Scientific Officer [Blagica Penova-Veselinovic](#), examined the epigenetic profile – the non-genetic influences on how a person's genes are expressed – of 303 teenagers born via IVF. They compared this to the epigenetic profile of 1,188 members of the Raine Study, a group of young people who had been conceived naturally, without IVF assistance.

They found no difference in the DNA analysis between the two sets of children.

Professor Hart said the study was largest and most detailed of its kind to-date, and that the conclusions reached by the study will provide great reassurance to IVF children, their families, and all those currently undergoing and considering IVF treatment.

The unique value of The Raine Study

For researchers in Australia and around the world, this study illustrates the value of having access to the data held by a longitudinal cohort study. In the case of the Raine Study, data has been collected from the same nearly 2,900 participants at regular intervals for over 30 years, since before they were born through to adulthood – at 1, 2, 3, 5, 8, 10, 14, 17, 18, 20, 22, 27 and 28 years of age. Future follow-ups continue to be planned.

More than 30,000 pieces of data and over 30 million pieces of genetic information has been collected on each of these participants, creating a very powerful pool of data which sheds light on the longitudinal effects of environmental as well as genetic factors. As in the case of this IVF study,



Appendix: List of Raine Study Publications 2021

1. Ayano G, Betts K, Lin A, Tait R, Alati R. Maternal and paternal mental health problems and the risk of offspring depression in late adolescence: findings from the Raine study. *J Ment Health*. 2021;1-9.
2. Ayano G, Betts K, Lin A, Tait R, Alati R. Associations of maternal and paternal mental health problems with offspring anxiety at age 20 years: Findings from a population-based prospective cohort study. *Psychiatry Res*. 2021;298:113781.
3. Ayano G, Betts K, Tait R, Dachew BA, Alati R. Maternal depressive and anxiety symptoms and the risk of attention deficit hyperactivity disorder symptoms in offspring aged 17: Findings from the Raine Study. *J Affect Disord*. 2021;284:149-56.
4. Ayano G, Lin A, Betts K, Tait R, Dachew BA, Alati R. Risk of conduct and oppositional defiant disorder symptoms in offspring of parents with mental health problems: Findings from the Raine Study. *J Psychiatr Res*. 2021;138:53-9.
- 5*. Ayano G, Lin A, Dachew BA, Tait R, Betts K, Alati R. The impact of parental mental health problems on the educational outcomes of their offspring: Findings from the Raine Study. *Aust N Z J Psychiatry*. 2021;48674211025633.
6. Beales D, Beynon A, Jacques A, Smith A, Cicuttini F, Straker L. Insight into the longitudinal relationship between chronic subclinical inflammation and obesity from adolescence to early adulthood: a dual trajectory analysis. *Inflamm Res*. 2021.
7. Berman YeE, Doherty DA, Main KM, Frederiksen H, Hickey M, Keelan JA, et al. Associations between Prenatal Exposure to Phthalates and Timing of Menarche and Growth and Adiposity into Adulthood: A Twenty-Years Birth Cohort Study. *International Journal of Environmental Research and Public Health*. 2021;18(9).
8. Beynon AM, Hebert JJ, Beales DJ, Jacques A, Walker BF. Multi-trajectory analysis of C-reactive protein and low back pain from adolescence to early adulthood. *Eur Spine J*. 2021.
9. Bräuner EV, Koch T, Juul A, Doherty DA, Hart R, Hickey M. Prenatal exposure to maternal stressful life events and earlier age at menarche: the Raine Study. *Hum Reprod*. 2021.
10. Bräuner EV, Lim Y-H, Koch T, Mori TA, Beilin L, Doherty DA, et al. Sex-dependent associations between maternal prenatal stressful life events, BMI trajectories and obesity risk in offspring: The Raine Study. *Comprehensive Psychoneuroendocrinology*. 2021;7:100066.
11. Canfell OJ, Littlewood R, Wright ORL, Walker JL. i-PATHWAY: Development and validation of a prediction model for childhood obesity in an Australian prospective birth cohort. *J Paediatr Child Health*. 2021.
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13. Duko B, Pereira G, Betts K, Tait RJ, Newnham J, Alati R. Prenatal exposure to maternal, but not paternal, tobacco smoking is associated with smoking in adolescence. *Addict Behav*. 2021;117:106871.
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16. Haynes A, McVeigh J, Hissen SL, Howie EK, Eastwood PR, Straker L, et al. Participation in sport in childhood and adolescence: Implications for adult fitness. *J Sci Med Sport*. 2021.
- 17*. Huang RC, Melton PE, Burton MA, Beilin LJ, Clarke-Harris R, Cook E, et al. Adiposity associated DNA methylation signatures in adolescents are related to leptin and perinatal factors. *Epigenetics*. 2021;1-18.
18. Innes S, Jacques A, Scott K, Walker B. Early age at menarche is associated with post-menarche back pain: An analysis of the Raine Study. *Eur J Pain*. 2021.
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Legend: ^ Epub in 2020 and indexed in 2021

* Epub in 2021

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