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Cohort Profile

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Cohort Profile: The ORIGINS pregnancy and birth cohort

Jacqueline Davis [1,2,3,4,*] Zenobia Talati [1,2,4] Sarah Whalan,[1] Wesley Billingham,[1] Nina D'Vaz,[1,3] Lisa Gibson,[1,3] Susan L Prescott,[1,2,3,5,6] and Desiree T Silva[1,2,4,7,8]

[1]The Kids Research Institute Australia, Nedlands, WA, Australia, [2]Medical School, University of Western Australia, Crawley, WA, Australia, [3]School of Medical and Health Sciences, Edith Cowan University, Joondalup, WA, Australia, [4]School of Population Health, Curtin University, Bentley, WA, Australia, [5]Nova Institute for Health, Baltimore, MD, USA, [6]Family and Community Medicine, University of Maryland, Baltimore, MD, USA, [7]Joondalup Health Campus, Joondalup, WA, Australia and [8]Perth Children's Hospital, Nedlands, WA, Australia

*Corresponding author. The Kids Research Institute Australia, 15 Hospital Ave, Nedlands WA 6009, Australia. E-mail: Jackie.davis@thekids.org.au

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Key Features

- The ORIGINS cohort was established to identify what factors contribute to 'a healthy start to life', through a focus on childhood health and disease (including non-communicable diseases). Unique to the cohort is a range of nested harmonized studies (observational and interventional) aimed at addressing common health problems in early life.
- This prospective, longitudinal pregnancy cohort was established in 2016 to follow families living in the Joondalup and Wanneroo communities in Perth, Western Australia, over a decade. At the time of creation, children in this catchment had higher vulnerability scores on the Australian Early Development Census (AEDC) compared with State and National results.
- The final sample of 7254 active participants comprised 3448 women (mean age: 32, range: 17–50) and 3806 children enrolled at birth ($n = 1983$ boys and 1823 girls).
- Mothers, partners and children were (and continue to be) followed up for sample collections, paediatric appointments and questionnaires (including the Australian Eating Survey, Ages & Stages Questionnaire, Connors Early Childhood). Follow-up waves take place at multiple time points following birth, both in person and digitally at 1 year, 3 years and 5 years of age.
- Accessing the ORIGINS cohort, database or biological samples involves a process of review and approval. Please email [origins.research@thekids.org.au] for more information.

Why was the cohort set up?

Early onset non-communicable diseases (NCDs), including obesity, allergies, neurodevelopmental disorders and mental ill-health in childhood, present a serious and increasing threat to lifelong health and longevity.[1] A life course approach to health, commencing in early life, can provide new opportunities for addressing and halting the onset of ill health.[2] Fresh insights into mechanisms, particularly processes by which the developmental environment affects epigenetic progressions in the developing offspring, offer the prospect of identifying biomarkers of future risks[2] and protective factors.[3]

The ORIGINS cohort was developed to investigate the early life pathways to NCDs and other forms of ill health and to test novel, contemporary methods to curtail these.[4] ORIGINS' goal is to better understand how to optimize the early environment, preventing onset of ill health and delivering early interventions, thus creating 'a healthy start to life' for future generations. Although many NCDs encompass wide phenotypic variations, many are associated with chronic low-grade inflammation and immune dysfunction.[5] This commonality suggests shared causal pathways, indicating that they should be studied together rather than in isolation. Multi-NCD intervention strategies implemented prenatally and in early life are not only cost effective but also highly impactful.[6,7]

Longitudinal cohort studies provide unique and invaluable opportunities for community engagement, research and education aimed at investigating and remediating modern health challenges. The ORIGINS cohort was established in October 2016, recruiting families visiting the Joondalup Health Campus (JHC; a private/public partnership run by Ramsay Health Care) for their antenatal appointments. The Kids Research Institute Australia and Joondalup Health Campus are the partner institutions governing ORIGINS. JHC provides an ideal setting to embed a large-scale research cohort study within a clinical and diagnostic facility, enabling clinicians to hold research

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appointments alongside clinical duties and accelerating the pathways to translating research into practice.

JHC provides obstetric services to the Wanneroo and Joondalup communities located in the northern suburbs of Perth (the capital city of Western Australia). This region has experienced high population growth over the past few decades and there is a need for the infrastructure within this area to keep pace with the increasing demand for services.[8,9] JHC remains the only paediatric hospital with an Emergency Department providing services to children living in the Joondalup/Wanneroo region.[9] Children who live in the Wanneroo/Joondalup region have been shown to have scored lower on the Australian Early Development Census (AEDC) in one or more domains, indicating they were developmentally vulnerable compared with state and national scores. Thus, these children are potentially entering school with reduced learning capacity and capabilities. The AEDC is a reliable tool for assessing early childhood development and has been shown to predict later health, wellbeing and academic success.[10]

The ORIGINS cohort is investigating the origins of health and disease through the creation of a comprehensive data platform for research discovery. The data platform includes data from the collection of biological samples (including blood, saliva, buccal cells, urine, stool, hair, house dust, cord blood, placenta, amniotic fluid, meconium, breast milk and colostrum), clinical assessments [including body fat composition measurements such as PEA POD (for infants) and BOD POD (for adults and children)], skin prick test, eczema assessments and anthropometry) and self-report surveys (across domains including demographics, growth and development, medical, biological and genetic, biopsychosocial and cognitive and lifestyle, environment and nutrition).

ORIGINS was designed to provide the infrastructure to integrate multiple observational and intervention studies (known as 'sub-projects') to be nested within the main cohort. The data platform is available to researchers who apply for access and meet all the requirements to register as a sub-project within ORIGINS. These sub-projects are key to answering targeted research questions, testing early interventions and translating findings back into the community. All sub-projects must undergo a scientific and ethical review before gaining access to the cohort data/samples. Sub-projects nested within ORIGINS are harmonized in terms of their recruitment, exposures and outcomes measured. This method facilitates interdisciplinary collaboration and efficiencies and promotes a more holistic multisystem approach to achieving a healthier start to life. New data or samples collected by sub-projects are returned to the ORIGINS data platform for use by future sub-projects.[11]

Another key objective of ORIGINS is for research findings to be highly translational through the provision of real-time feedback to families and informing clinical practice and policy changes.[4] Unhealthy growth trajectories, mental ill health, allergic disease and developmental and neurodevelopmental delays/disorders can be identified when children present to ORIGINS for their clinical assessment at 1, 3 and 5 years. Real-time feedback is provided to the families and their general practitioner (GP) when potential issues are detected, along with referral to appropriate specialist supports.

Who is in the cohort?

The full ORIGINS cohort consists of 'non-active' and 'active' participants, providing families with two options for level of participation. Non-active families consent to provide ORIGINS with de-identified information from routine hospital data collections (databank and biobank information) and the potential for data linkage to both WA and Australian Government Data. Recruitment of non-active participants is ongoing and will continue until 6000 families have been recruited. Active families provide ORIGINS with the same information as non-active families and additionally are invited to complete questionnaires (see Tables 1 and 2), provide biological samples and attend clinic appointments. Recruitment of active participants ceased in February 2023 when 4000 mothers were recruited, and the last birth took place in July 2023. This cohort profile presents detailed information on active participants only.

Figure 1 provides an overview of participant recruitment and retention across the antenatal and birth time points. Women were approached across one or more pregnancies (with a total of 17 403 invitations made at the antenatal appointment or at birth) to participate in the study. Of these, 5348 pregnancies (31%) were enrolled into the non-active participation arm and 4012 (23%) pregnancies were enrolled into the active participation arm. There were 8043 pregnancies (46%) in which the women declined to participate. A total of 3806 babies (3686 singletons, and 60 twins) were born to 3630 women who consented to be active participants at birth (with some women enrolling multiple pregnancies).

Table 3 provides a comparison of key demographic variables among participants who were followed up at delivery ($n = 3746$) and those who did not consent their child ($n = 186$). Women who were not followed-up at birth were more likely to be those with twins (compared with singletons) and those of a slightly lower socioeconomic background [according to their Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) decile]. Participants who formally withdrew at birth and gave a reason cited time burden, moving away, confidentiality concerns or no longer wishing to be in the study.

Compared with other women who birthed at JHC but did not enrol in ORIGINS, ORIGINS participants were approximately 10 months older, had slightly higher body mass index (BMI) (by 0.11 points) and were slightly more advantaged, scoring 0.20 decile points higher on the IRSAD. These differences were small and thus not concerning for the representativeness of the sample.

How often have they been followed up?

The birthing partner (mothers), non-birthing partners (typically fathers) and children are being followed up for data and biological samples at 15 time points across the antenatal, birth and postnatal periods (see Table 1). We maintain an 'open door' policy similar to that of the Generation Victoria birth cohort,[38] in that participants can opt out of data and sample collections at any time point without consequences for overall study participation. This results in varying compliance rates across time points, but has given participants who are momentarily unable to engage for personal reasons (including being busy with young children), the opportunity to re-engage at future time points rather than withdraw from the project.

In addition to the follow-up time points shown in Table 1, approved sub-projects can invite a subset of ORIGINS participants to provide data or samples at separate time points.

Table 1. ORIGINS biological and data collections for mother, non-birthing partner and child in the active cohort

	Antenatal		Postnatal			Childhood						
Data source	20 weeks' gestation	36 weeks' gestation	Birth	2/4 months[d]	6/9 months[d]	1 year[d]	1.5 years[d]	2 years[d]	3 years[d]	3.5 years[d]	4 years[d]	5 years[d]
Questionnaires												
ORIGINS Core Questionnaire	M, P	M		M, C	M, C	M, C	M, C	M, C		M, C	M, C	M, C
Ages & Stages Questionnaire[a]				C	C	C		C	C		C	C
Australian Eating Survey[a]	M, P	M			M	M						
Infant Food Frequency Questionnaire[a]						C		C	C			C
Conners Early Childhood[a]									C			C
Strengths and Difficulties Questionnaire[a]									C			C
JHC Health Questionnaire	M, P											
JHC Antenatal Questionnaire	M	M										
JHC Birth & Postnatal Questionnaire			M, C									
JHC Special Care Nursery (database)			C									
Biobank collections												
Blood	M, P	M				C			C			C
Urine	M	M		M, C	M, C	C			C			C
Buccal swab	M, P	M	P			M, C			C			C
Saliva	M, P	M	P			M, C			C			C
Stool	M	M		M, C	M, C	C			C			C
House dust		M				M			M			M
Meconium			C									
Cord blood			C									
Cord tissue			C									
Placenta			C									
Colostrum			M									
Breast milk				M	M	M						
Hair		M				M						
Teeth												C
Clinical assessment												
PEA POD[b]			C									
BOD POD[c]									C			C
Skin prick test						C			C			C
Eczema assessment						C			C			C
Anthropometry						C			C			C
Developmental review						C			C			C

C, child; JHC, Joondalup Health Campus; M, mother; P, partner.
[a] Standardized questionnaires.
[b] Air displacement plethysmography system using whole-body densitometry to determine body composition (fat and fat-free mass) in infants weighing between 1 and 8 kg.
[c] Air displacement plethysmography system using whole-body densitometric principles to determine body composition (fat and fat-free mass) in adults and children.
[d] Ongoing follow-up time points that have not been closed yet.

Table 2. Examples of variables and standardized questionnaires measured during the antenatal period, categorized by domain of research

Domain	Example variables and standardized questionnaires
Demographic	Language, ethnicity, education, employment, household income, gestational weight gain
Growth and development	Ages and Stages Questionnaire,[12] Conner's Early Childhood[13]
Medical, biological and genetic	COVID diagnosis and vaccinations, musculoskeletal pain, prescription medication use, oral health
Biopsychosocial and cognitive	Connor-Davidson Resilience Scale Short Form,[14] Depression Anxiety Stress Scales (DASS-21),[15] Attachment Scale,[16,17] Perceived Social Support Scale,[18,19] Stressful Life Events,[20] Mental Health Continuum[21]
Lifestyle, environment and nutrition	Drinking water, cooking, electronic devices in the household, technology or internet use, alcohol, smoking and drug use[22], physical activity,[23] Godin Leisure Time,[24] Health Related Quality of Life,[25] childcare, playgroup and play time, Brief-Infant Sleep Questionnaire,[26] Pittsburgh Sleep Index,[27] Buckner's Neighbourhood Cohesion,[28] Neighbourhood Environment Walkability Scale,[29] connectedness to nature,[30] nature play, nature-relatedness,[31] time in the sun, Australian Eating Survey,[32,33] Food Frequency Questionnaire,[34] Infant Food Frequency Questionnaire,[35] Mediterranean Diet Index,[36] breastfeeding awareness

Figure 1. Flow chart of participant recruitment and retention over the antenatal and birth time points. Women were eligible to enrol multiple times, to allow for additional pregnancies

This may be to implement a collection measure which is not part of the core protocol, or to invite a specific sub-set of the ORIGINS participants (e.g. families with a history of allergies) for data collection. Table 1 only shows the follow-ups that all active ORIGINS participants are invited to take part in, as part of the core ORIGINS collections. The follow-up time points/collections that are initiated by specific sub-projects will change over the course of the project: for example, when new sub-projects join and create new time points/collections and when the sub-project is completed. Furthermore, sub-projects that collect new data or samples which are not part of the core ORIGINS protocol are asked to return this to ORIGINS for future use by other researchers.

What has been measured?

Table 1 provides details of the data and biological samples collected at various time points from active participants. Data collections are a mix of questionnaires created specifically for this project (I.e. the ORIGINS Core Questionnaire), hospital questionnaires and records, and pre-existing standardized questionnaires. The ORIGINS Core Questionnaire is administered online across multiple time points and includes a range of validated survey questions in relevant domains (see Table 2). At the pregnancy and birth time points, pregnant women and their partners (if available) were asked to complete measures of demographic information (such as ethnicity, education, employment, income, location of residence), use of alcohol, drugs and medications, mental health, weight, diet, physical activity, engagement with nature, and screen use. Later iterations of the questionnaire sent to participants at follow-ups contain some combination of scales measuring the above-mentioned domains plus situational changes including COVID-19 infections, technology use and quality of life. Items relating to the child are completed by a parent on behalf of the child. Items relating to the

Table 3. Sociodemographic characteristics of mothers in the active cohort, comparing those who did and did not consent their baby after delivery

Characteristic	*n*	Total pregnancies	Followed up at birth	Not followed up	Mean difference (95% CI)	*P*[a]
Total *n*	3932	3932	3746	186		
Age at birth (years)						
Mean (SD)		32.25 (4.65)	32.29 (4.63)	31.46 (4.96)	0.84 (0.10, 1.60)	0.025
Minimum–maximum		17–50.20	17–50.20	18.46–44.90		
Pre-pregnancy BMI[b]	3653					
Mean (SD)		25.71 (5.30)	25.71 (5.26)	25.60 (6.19)	0.11 (–0.99, 1.20)	0.840
Minimum–maximum		14.69–65.11	14.69–65.11	15.06–45.79		
Unknown/missing		279	220	59		
Previous pregnancies (gravidity)	3475				NA	NA
0		1361 (39.17%)	1361 (39.17%)	0		
1		1016 (29.24%)	1016 (29.24%)	0		
2		587 (16.89%)	587 (16.89%)	0		
3		266 (7.65%)	266 (7.65%)	0		
4 or more		245 (7.05%)	245 (7.05%)	0		
Unknown/missing		457	271	186		
Birth	3850				NA	0.030
Singleton		3785 (98.31%)	3686 (98.40%)	99 (95.19%)		
Twins[c]		65 (1.69%)	60 (1.60%)	5 (4.81%)		
Unknown/missing		82	0	82		
Education	3049				NA	0.747
Less than Year 10		18 (0.59%)	18 (0.61%)	0		
Year 10, 11 or equivalent		173 (5.67%)	168 (5.67%)	5 (5.68%)		
Year 12 or equivalent		510 (16.73%)	493 (16.65%)	17 (19.32%)		
Trade certificate/apprenticeship		561 (18.40%)	541 (18.27%)	20 (22.73%)		
Bachelor degree		1104 (36.21%)	1075 (36.31%)	29 (32.95%)		
Postgraduate degree		554 (18.17%)	538 (18.17%)	16 (18.18%)		
Other		129 (4.23%)	128 (4.32%)	1 (1.14%)		
Unknown/missing		883	785	98		
IRSAD decile[d]	3924					
Mean (SD)		7.82 (1.71)	7.83 (1.70)	7.63 (1.77)	0.20 (–0.06, 0.46)	0.134
Minimum–maximum		1–10	1–10	2–10		
Unknown		8	8	0		
Ethnic origin	3522				NA	NA
Aboriginal (not Torres Strait Islander)		8 (0.23%)	8 (0.23%)	0		
African		112 (3.18%)	112 (3.18%)	0		
Caucasian		2912 (82.68%)	2910 (82.67%)	0		
Indian		176 (5%)	176 (5%)	0		
Maori		12 (0.34%)	12 (0.34%)	0		
Other		284 (8.06%)	284 (8.07%)	0		
Polynesian		18 (0.51%)	18 (0.51%)	0		
Unknown/missing		461	277	186		

BMI, body mass index; CI, confidence interval; IRSAD, Index of Relative Socio-economic Advantage and Disadvantage; SD, standard deviation.
[a] Welch two sample t test for continuous variables; Fisher's exact test for categorical variables.
[b] BMI cut offs based on [https://www.health.gov.au/topics/overweight-and-obesity/bmi-and-waist].
[c] There were no multiple births greater than twins.
[d] Australian Bureau of Statistics Socio-economic Indices for Areas (SEIFA) Index of Relative Socio-economic Advantage and Disadvantage (IRSAD),[37] which summarizes information about the economic and social conditions of people and households within an area, including both relative advantage and disadvantage measures.

non-birthing partner can be completed by either the mother or the non-birthing partner and this information is captured as part of the questionnaire.

The Australian Eating Survey[32,33] was sent to mothers and their partners for completion during the antenatal period to assess nutrition and dietary intake against Australian norms. Two hospital questionnaires were completed during antenatal visits: (i) a health questionnaire completed by mothers and their partners (assessing height, weight, fertility, any medical/developmental/mental health conditions, allergies, medical history, breastfeeding history and intentions, vaccinations, family status and living arrangements, and medication, alcohol and drug use); and (ii) an antenatal questionnaire (containing additional information on urine and blood test results). ORIGINS also has access to the Midwives' Notification System, a statutory data collection from JHC that collects data at birth (containing details of the mother's medical and pregnancy complications, delivery and birth outcomes). Details of any visits to the hospital Special Care Nursery were recorded for each baby. The ORIGINS team do not impute data when cases are missing. This is the responsibility of sub-project researchers, to be conducted in a way to suit the purpose of their specific datasets and research questions.

The schedule for collection of biological samples from active participants is shown in Table 1, and further details on the collection, processing and storage of biological samples can be found in The ORIGINS Biobank protocol paper.[39]

Table 4. Summary of select studies using the ORIGINS cohort with published findings

Participants	Methods	Key finding	Citation
Inflammation and allergies			
109 pregnant women	Women were randomized at 36 weeks' gestation to one of two dietary intervention groups: (i) at least 6 eggs and at least 60 peanuts per week (high egg and peanut diet); or (ii) up to 2 eggs and up to 20 peanuts per week (low egg and peanut diet)	Regular peanut consumption during breastfeeding provides the infant with a regular source of peanut allergen in early life to develop tolerance and reduce peanut sensitization and peanut allergy. However, results appear to potentially favour lower maternal egg consumption during breastfeeding to reduce infant egg allergy. Hence, maternal consumption levels of different food allergens may lead to allergen-specific infant outcomes, which requires further investigation in larger future trials	Palmer DJ, Silva DT, Prescott SL. Maternal peanut and egg consumption during breastfeeding randomized pilot trial. *Pediatric Allergy and Immunology* 2022;**33**:e13845[40]
52 pregnant women	Pregnant women were stratified for persistent high and low alignment to a Mediterranean Diet (MD) based on validated MD questionnaires completed twice during pregnancy. ^{1}H-NMR spectroscopy was used to investigate the metabolite profile in urine and serum of these women at 36 weeks of pregnancy. This was compared with MD alignment and dietary intake assessed by food frequency questionnaire at 36 weeks. The relationship between diet, metabolite profile and inflammatory status was investigated by using a panel of biomarkers including GlycA and GlycB	Metabolite profiles of pregnant women who had a high alignment with the Mediterranean diet were significantly different from pregnant women who had a low alignment with the Mediterranean diet. These metabolite profiles aligned with self-reported food intake. Strong (or high) alignment with a Mediterranean diet was associated with lower biomarkers of systemic inflammation and increased concentrations of selected gut-microbial metabolites	Rowley C, Lodge S, Egan S *et al.* Altered dietary behaviour during pregnancy impacts systemic metabolic phenotypes. *Front Nutr* 2023;**10**:1230480[41]
Mental health			
84 pregnant women	The aim of this study was to characterize participant engagement and experience in an antenatal, digital, emotional wellbeing, pilot, randomised controlled trial based on wellbeing training in mindfulness, self-compassion or general relaxation	Pregnant women in this study found digital mental health interventions (DMHIs) based in meditation practices appealing and feasible. This research will enable future app designs that are sufficiently nuanced to maximize the uptake, engagement, and application of mental health skills and contemplative practices in the perinatal period	Davis JA, Ohan JL, Gregory S *et al.* Perinatal women's perspectives of, and engagement in, digital emotional well-being training: mixed methods study. *J Med Internet Res* 2023;**17**:25:e46852[42]
Diet			
458 pregnant women in their third trimester of pregnancy, and their newborns	Maternal participants completed a questionnaire on Mediterranean Diet adherence (MDA) and were categorized into three categories (low, medium or high) based on the overall score from 13 questions. Infant's body composition was measured through a PEA POD within 7 days of birth	Infants born to mothers with high Mediterranean Diet adherence (MDA) had a body fat percentage of 11.3%, whereas infants born to mothers with low MDA had a higher body fat percentage of 13.3% ($P = 0.010$). When adjusted for pre-pregnancy body mass index and infant sex, a significant result remained between high vs low MDA and infant fat mass (FM) (2.5% less FM $P = 0.016$). This study suggests that high MDA in pregnancy was associated with a reduced body fat percentage in the newborn.	Ashwin D, Gibson L, Hagemann E, D'Vaz N, Bear N, Silva D. The impact a Mediterranean Diet in the third trimester of pregnancy has on neonatal body fat percentage. *J Dev Orig Health Dis* 2022;**13**:500–07[43]

(continued)

Table 4. (continued)

Participants	Methods	Key finding	Citation
Screen use			
Thirty families of infants (aged 9–15 months)	Interviews were conducted to explore how parents and infants use mobile touch screen devices (such as smartphones and tablets), and how device use influenced parents' thoughts, feelings and behaviours towards their infant and other family interactions	Two-thirds of infants were routinely involved in family video calls and one-third used devices for other purposes. Parent and/or child device use served to both enhance connection and increase distraction between parents and infants and between other family members. The findings highlight a new opportunity for how hardware and software should be designed and used to maximize benefits and reduce detriments of device use, to optimize parent-infant attachment and child development	Hood R, Zabatiero J, Silva D, Zubrick SR, Straker L. 'It helps and it doesn't help': maternal perspectives on how the use of smartphones and tablet computers influences parent-infant attachment. *Ergonomics* 2024;**67**:148–67[44]
Dental health			
42 children aged under 4 years	A cross-sectional study in which children were visually examined by a paediatric dentist and subsequently had dental photographs taken by parents using a smartphone camera. Two trained oral health professionals asynchronously evaluated the photographs. The presence of dental caries was recorded, and the diagnostic accuracy and reliability of the tele-dental screening and the dental examinations were compared	Tele-dental screening for early childhood caries was shown to be a feasible approach following a brief training for primary caregivers. Parents were able to take good quality photographs, with 90% of photographs rated as good to fair quality. Tele-dental screening demonstrated high specificity (>=95.5%) for both reviewers compared with the dental examination. This approach can offer a potential low-cost and sustainable alternative for visual dental examinations for young children	Azimi S, Estai M, Patel J, Silva D. The feasibility of a digital health approach to facilitate remote dental screening among preschool children during COVID-19 and social restrictions. *Int J Paediatr Dent* 2023;**33**:234–45[45]

PEA POD, air displacement plethysmography system using whole-body densitometry to determine body composition (fat and fat-free mass) in infants weighing between 1 and 8 kg.

What has been found?

A complete list of publications can be found at [https://originsproject.thekids.org.au/about-origins/papers-publications/]. Table 4 summarizes some of the key findings from sub-projects using ORIGINS data, samples and/or participants.

What are the main strengths and weaknesses?

A strength of the cohort is the depth of data and samples available to researchers. Data and biological samples are gathered across multiple time points, across a wide range of domains, and are available for not just the mother and child but also the partner and in some cases the siblings. The cohort allows for sub-projects of any design (observational or interventional) to be nested within the cohort, thus avoiding the 'wait and watch' approach and allowing for action and early intervention. Sub-projects may request to gather new data and samples outside of the core protocol. When they do, the data is returned back to the ORIGINS data platform and made available to future researchers. The ORIGINS data platform is building capacity within the next generation of researchers, with 42 students currently engaged in projects through ORIGINS.

The volume and range of data/samples collected within the ORIGINS cohort is a key strength; however, the management and integration of so many complex datasets have been a significant challenge. Over the past year (2023), the ORIGINS data collections have been centralized into one platform enabling rapid data extraction across multiple domains. Additionally, researchers can preview the metadata (e.g. items available and completion rates) through an external self-serve data visualization website and can request access to the data platform for research purposes at: [https://app.powerbi.com/view?r=eyJrIjoiYWQxMzZiZTctZTZmZi00YmYyLWE4MTYtM2FiNGM1N2Q5Zjg3IiwidCI6IjA0ZjA4OWFjLTgxMWItNDNjMC05OWNmLTc3MjE4NmVlNjQwMCIsImMiOjEwfQ%3D%3D].

Another strength of the cohort lies in the high level of engagement with participants. Participants are provided with real-time feedback (e.g. results from clinic appointments and assessments) to ensure health conditions are identified early. Participants are also invited to regular events which run throughout the year, ranging from small (drop-in coffee and play sessions) to large (an annual family event). There is a dedicated participant reference group made up of parents enrolled in ORIGINS who regularly provide input, guidance and feedback on all aspects of ORIGINS, including reviewing new proposed sub-projects. This group is represented in the ORIGINS governance structure and meets biannually, with additional ad hoc meetings and contact via e-mail and phone when required. Sub-projects will often have their own ORIGINS parent who acts as a consumer representative for that project and provides

input into the unique aspects of the study. ORIGINS liases with participants to facilitate this connection for sub-projects.

Although efforts are made to keep participants engaged and motivated, a weakness of the cohort is the variability in completion rates across the questionnaires. The self-report questionnaires administered at some time points are quite lengthy and compliance decreases with the increasing time required to complete the questions. Another weakness of the cohort is the lack of diversity within the sample. Since the cohort was drawn from families presenting to JHC for their antenatal appointments, the cohort tends to be skewed towards more affluent, Caucasian, middle-class families, with limited representation of Aboriginal and Torres Strait Islander people and culturally and linguistically diverse families.[4] Additionally, all the recruitment material and questionnaires are in English and no translation services are offered, meaning the families must be literate in English to be able to participate.

Can I get hold of the data?

ORIGINS offers an unparallelled opportunity for researchers to access one of the richest collections of contemporary data in the world on children and their parents in the early years. Not only do researchers have the opportunity to access multiple longitudinal datasets, there is also the ability for them to embed interventions and clinical trials in this cohort with existing infrastructure and resources. Researchers interested in accessing the ORIGINS cohort, database or biological samples must undergo a process of scientific review and approval. Once the sub-project is approved, the researchers will need to pay cost recovery fees for access to the data, samples and/or cohort. An accurate quote will be provided during the application process, based on the unique needs of the project. Requests for access can be made through e-mail to: [origins.research@thekids.org.au] or by contacting Jacqueline Davis (Co-Director) at: [jackie.davis@thekids.org.au]. Further information can also be found in ORIGINS Collaboration Policy available at: [https://originsproject.thekids.org.au/for-collaborators/].

Ethics approval

ORIGINS was conducted according to the guidelines of the Declaration of Helsinki. The study was approved by the Ramsay Health Care WA I SA Human Research Ethics Committee (ref: 1440).

Data availability

See 'Can I get hold of the data?' above.

Author contributions

Z.T. and J.D. prepared the manuscript with input from L.G., D.T.S., S.L.P. and N.D. W.B. and S.W. performed the data analysis. All authors reviewed the manuscript prior to publication.

Use of artificial intelligence (AI) tools

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Conflict of interest

None declared.

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Cohort Profile