


Asylum seeking children and adolescents in Australian immigration detention on Nauru: a longitudinal cohort study

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ABSTRACT

Introduction Immigration detention has a profound and negative impact on the physical health, mental health, development and social-emotional well-being of children, adolescents and their families. Australian clinicians will report results from detailed health and well-being assessments of asylum seeking children and adolescents who have experienced prolonged immigration detention.

Methods and analysis This is a national, multicentre study with a longitudinal cohort design that will document health and well-being outcomes of the children and adolescents who have been detained in offshore detention on the remote island of Nauru. Outcome measures will be reported from the time arrival in Australia and repeated over a 5-year follow-up period. Measures include demographics, residency history and refugee status, physical health and well-being outcomes (including mental health, development and social-emotional well-being), clinical service utilisation and psychosocial risk and protective factors for health and well-being (eg, adverse childhood experiences). Longitudinal follow-up will capture outcomes over a 5-year period after arrival in Australia. Analysis will be undertaken to explore baseline risk and protective factors, with regression analyses to assess their impact on health and well-being outcomes. To understand how children's outcomes change over time, multilevel regression analysis will be utilised. Structural equation modelling will be conducted to explore the correlation between baseline factors, mediational factors and outcomes to assess trajectories over time.

Ethics and dissemination This research project was approved by the Sydney Children's Hospitals Network Human Research Ethics Committee. Subsequent site-specific approvals have been approved in 5 of the 11 governing bodies where the clinical consultations took place. In order to ensure this research is relevant and sensitive to the needs of the cohort, our research team includes an asylum seeker who has spent time in Australian immigration detention. Results will be presented at conferences and published in peer-reviewed Medline-indexed journals.

What is already known on this topic?

- ▶ The number of forcibly displaced people worldwide is the highest on record and over half of these are children and adolescents.
- ▶ The health and well-being of asylum seeking children and adolescents is a major global public health concern.
- ▶ Immigration detention is known to have a negative impact on children and adolescents' mental health, physical health, development, social and emotional well-being.

What this study hopes to add?

- ▶ This protocol describes the methods to undertake a longitudinal cohort study of children and adolescents who have been detained in immigration detention.
- ▶ We will document the immediate and long-term physical health, mental health, development and social-emotional well-being of children and adolescents who have experienced prolonged detention.
- ▶ Understanding the immediate and long-term impact of detention may allow us to mitigate harm by informing policy nationally and internationally.

INTRODUCTION

1.1 Background

There are an estimated 70.9 million forcibly displaced people worldwide, the highest level on record; over half of these are children and adolescents. Around 85% of people globally are displaced internally or in neighbouring developing countries, with a small percentage reaching North America, Europe and Australasia.¹ Displaced children, adolescents and adults face multiple physical and mental challenges pre-migration and in transit and continuing hardships post-migration.²⁻⁵ The United



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Nations High Commissioner for Refugees (UNHCR) manages programmes to resettle people whose claim for refugee status has been recognised and who remain at risk, but less than 1 per cent of the world's refugees are resettled in this way. Australia formally participates in the UNHCR resettlement programme accepting 12 000 to 20 000 refugees a year after their asylum claims have been processed overseas.⁶ Once resettled in Australia, social security payments and access to the universal healthcare system, including reduced price pharmaceutical benefits, are provided consistent with Australian citizens and other permanent residents.⁷

Many wealthy reception countries now employ restrictive detention practices while protection applications are processed for people who arrive onshore and seek asylum. Since 1992 Australia has been unique in mandating indefinite incarceration of all children and adults arriving 'unauthorised' by boat. Australia has also imposed increasingly restrictive policies even for those found to be refugees. These include denial of permanent resettlement, various forms of temporary protection and limited access to work, healthcare, higher education and family reunion.^{8,9}

Consistent with the global trend to prevent displaced populations from making asylum claims, the Australian Government developed Regional Settlement Arrangements with the Governments of Nauru and Papua New Guinea (PNG) in 2013.¹⁰ Under this, families and children seeking asylum were transferred to Nauru for processing and resettlement. By early 2019 all children and families held by the Australian government on Nauru since 2013 were transferred to Australia for medical care and into various forms of community detention. This very protracted offshore detention is unprecedented even by Australian standards. The extent of the negative effects on physical and mental health of the known 222 children held on Nauru during this period both in the immediate and long-term is unknown. This policy is still in place leaving the status of over 600 adults unresolved as at 30 September 2019.¹¹

Local and international studies confirm the profound negative impact of detention on physical health, mental health and well-being in children, adolescents and adults.^{3 4 7-10 12-22} The severity of mental distress is shown to increase with the amount of time spent in detention. Common psychiatric diagnoses in children include depression, anxiety, post-traumatic stress disorder (PTSD) and somatisation in addition to described emotional, behavioural and developmental difficulties.⁷

Findings in some studies are that post-migration stressors (including experiences of detention, discrimination and relocations, unsupportive social environments and parental mental illness) are more predictive of psychological problems than adverse experiences before arrival.^{4 22-28} Practices in the reception country have the potential to reduce cumulative risk and enhance protective factors to positively influence health and well-being outcomes.^{2 4 23 29}

Only one study has undertaken a comparison of the mental health of resettled refugee children who were not detained with those who were held in closed detention.¹² This cross-sectional study demonstrated that children with similar pre-arrival adversity and detained on Christmas Island, another processing centre for Australia, had worse social-emotional well-being outcomes than children not detained.¹² There is a dearth of appropriately designed longitudinal studies in the literature documenting the long-term impact of immigration detention in children. This is of global importance given the potential to avert the developmental and long-term consequences.³⁰

1.2 Objectives

There are many practical and political challenges to working with this cohort of children, but Australia is unfortunately in a unique position to undertake a study of asylum seeking children who have been in immigration detention for prolonged periods. We aim to document the impact of detention on the health and well-being over time on the children and adolescents detained on Nauru. Paediatricians and child psychiatrists across Australia who specialise in refugee health are part of an organised network, known as the 'Australian Refugee Child Health (ARCH) Network'. They provided evidence-based care to the majority of children that were detained on Nauru, including telehealth consultations prior to transfer and comprehensive medical assessments on arrival; follow-up will include ongoing annual clinical reviews post-arrival. Understanding the immediate and long-term impact of detention may allow us to mitigate harm through sharing this knowledge with international colleagues and to inform policy nationally and internationally.

2. METHODS AND ANALYSIS

2.1 Study design

This is a longitudinal study of children and adolescents who were detained in Australian offshore detention. We will describe their physical health, mental health, development, social and emotional well-being at baseline (prior to transfer or on arrival in Australia) and over a 5-year follow-up period after transfer to Australia. Retrospective data will be extracted from existing medical records, and participants' health and well-being will be tracked at annual consultations for 5 years post-arrival in Australia. Follow-up will incorporate usual clinical assessment, an interview schedule and standardised assessments of social and emotional well-being.

Study sample

Children and adolescents (younger than 18 years at the time of initial immigration detention) who were known to be in immigration detention or offshore processing on Nauru will be eligible for this study. The clinicians from the Australian Refugee Child Health Network have agreed to be co-investigators on this study, to identify eligible participants and to invite them and/or their legal

parent/guardian to participate, thereby minimising the introduction of unfamiliar staff to participants.

2.3 Study context

The Nauru Processing Centre was a locked and guarded immigration detention centre with no freedom of movement until October 2015, when it became an 'open centre', giving people limited freedom of movement. Asylum seekers were mostly accommodated in family groups although transfer to Australia for illness and other administrative reasons did result in family separation. Multiple human rights violations, limitations in agency and autonomy and continuing exposure to violence and trauma were described.⁸ For children this included experiences constituting neglect and maltreatment.^{8 9 13 31} Conditions included overwhelming heat, overcrowded tents and close proximity to open-pit phosphate mining, causing recurrent asthma and irritation of the eyes and skin. Secrecy and restricted public and press access has resulted in no published evidence on the long-term health of detainees in PNG and Nauru.^{8 10 31}

Publicly accessible data is mostly available for both Nauru and PNG combined. Since 2012, 4177 people went sent to Nauru or PNG; 222 children, of whom at least 27 were unaccompanied, were sent to Nauru. The population sent to Nauru was largely composed of asylum seekers from Sri Lanka, Pakistan, Bangladesh and people who were Stateless. Until October 2016, around 80% of detainees were found to be refugees. Four were settled in Cambodia, at least 503 were returned to their home countries, 1117 were transferred to Australia for medical or other reasons, but not granted permanent residency, and 632 settled in the USA. The last child was transferred off Nauru in February 2019. Many children and families remained on Nauru for close to 5 years awaiting resettlement.^{11 32}

Variables

Measures that will be collected are demographics (including residency history and refugee status), physical health, clinical characteristics and psychosocial risk and protective factors. The key outcome measure of interest is well-being, including mental health, development and social-emotional well-being. For follow-up reviews, clinicians will be asked to use an interview schedule and standardised instruments for the assessment of their patient's mental health (the Child Stress Disorders Checklist for PTSD), and the Strengths and Difficulties Questionnaire (SDQ) for social-emotional well-being.

2.5 Demographics

Demographic details include the child's date and place of birth, gender, ethnic background, countries of origin and transit, primary language spoken, date of arrival in Australia, family composition, parents' education, employment status and health, and financial hardship as a barrier to accessing healthcare. Residency history, including the duration and frequency of detention, and current refugee status will be collected.

Psychosocial risk and protective factors

Known or suspected risk and protective factors will be categorised into child, family and settlement factors. This includes Refugee-specific Adverse Childhood Experiences (R-ACE), such as prolonged transit, interrupted education and witnessing trauma,³³ as well as the standard Adverse Childhood Experience (ACE) measures, such as psychological, physical and sexual abuse and household dysfunction (substance abuse, parental mental illness, mother treated violently and criminal behaviour in the household).³⁰ Scoring for the ACE is based on the sum of childhood abuse and household dysfunction categories, with a score of 0 indicating no exposure, and a score of 7 indicating exposure to all categories.³⁰

Physical health and clinical characteristics

Diagnoses will be coded according to the Australian Modification of the International Statistical Classification of Diseases and Related Health Problems (ICD-10-AM), an expanded version of the WHO ICD-10. Additional physical health measures include height, weight, body mass index, immunisation status, oral health, medication and other treatments. Clinical characteristics include who performed the health assessments, their frequency and location, access to healthcare and length of stay if inpatient admission was required.

Outcome measure: well-being

Well-being outcomes are categorised into medical and mental health diagnoses, developmental difficulties or disabilities and social-emotional well-being.

As not all mental health symptoms experienced by children and adolescents reach the threshold for a Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) diagnosis, sub-diagnostic mental health symptoms will be dichotomously coded as 'yes' or 'no'. This includes Pervasive Refusal Syndrome symptoms³⁴ and PTSD symptoms.³⁵

Developmental difficulties or disabilities will be categorised by age (preschool and school aged children/adolescents). Clinicians will report on developmental delay, regression, learning difficulties, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder and others. If neither screening nor formal assessment was undertaken, clinicians will provide a clinical impression of their patient's neurodevelopmental status.

The SDQ will be used to measure social-emotional well-being and includes 25 items, with five symptom subscales assessing emotional symptoms, conduct problems, hyperactivity and inattention, peer relations and prosocial behaviour.^{36 37}

2.9 Data sources and storage

Data will be collected using a Research Electronic Data Capture (REDCap) survey, a secure web-based application to support research data collection.³⁸ Critical REDCap security components involve user authentication and role-based security to ensure that all survey



data entered are confidential and secured with restricted access to research personnel. Sensitive identifying information will be stored separately from any data analysis files in a secure location on UNSW OneDrive, accessible only to the study team.

2.10 Statistical methods

Data will be analysed in a de-identified format. Data analyses will demonstrate the proportion of participants who were diagnosed with a range of medical, mental health, developmental or social-emotional well-being conditions at baseline and follow-up. Follow-up data will include community or held residential detention, relocated or lost to follow-up. Outcomes of interest will include social-emotional well-being, and mental health symptoms and disorders.

Descriptive analyses will be undertaken to summarise means, variances and distributions of risk and protective factors at baseline and follow-up. Causal models will be developed to consider the complex relationships to physical and mental health outcomes. Structural equation modelling will be used to explore the causal relationships between predictors, mediational factors and outcomes (eg, mental health problems). Latent growth curve analysis will be utilised to examine the pattern of change in these outcomes over time.

PATIENT AND PUBLIC INVOLVEMENT STATEMENT

One of our core research study team (RR) has lived experience of detention as an asylum seeker in Australia, and in this way is similar to our patient cohort. He was involved in the study from the beginning, providing advice on key aspects of the study design, including the definition of the research questions, choice of the outcome measures and selection of relevant questions for the questionnaire. He will be involved in write-up and public dissemination of any research outputs.

Although we as authors support active involvement of patients as co-producers of research, we did not involve patients in this particular study. We considered patient involvement as inappropriate given that our patients are children and adolescents who have experienced prolonged detention in Australia's offshore processing system and whose immigration status remains uncertain. This project involves the collection of their data from their treating teams and does not seek to add to their stressors by requesting anything additional from them apart from consent and attending follow-up annually.

4. PARTICIPANT CONSENT

In order to maintain participant confidentiality and privacy, eligible participants and their parent/legal guardian will be invited to participate in the study by their usual clinician. This will occur at the next scheduled consultation or, where no consultation is scheduled within 2 months, clinicians will telephone participants

and invite them to a consultation for discussion about the study. During this consultation, clinicians will explain what participation will involve, that participation is voluntary, encourage eligible participants to ask any questions they may have and facilitate provision of consent to participate if they are interested. A qualified healthcare interpreter using participants' preferred language will be used to promote informed consent. Consent will be sought from both the child/adolescent participant and parent/legal guardian where the clinician deems the child/adolescent able to give informed consent, or from the parent/legal guardian only when the participant is not deemed competent and mature to give informed consent. Participants who reach the age of 18 years will be able to give their own consent.³⁹

Clinicians will present the two participation options below to children/adolescents and parents/guardians:

Participation option 1: retrospective

Participants consent to clinicians providing data from previous clinical consultations that took place from around the time of transfer to Australia, and up to the date of consent to this study. As this participation option involves already collected data, no additional time commitments are required from participants.

Participation option 2: retrospective data collection and prospective follow-up

Participation will involve Option 1 (retrospective data collection) PLUS consent to clinicians providing data from clinical consultations occurring over the coming 5 years. If no routine consultations are clinically required, then participants will be invited to attend an annual health and well-being assessment that will take approximately 1 hour.

Where participants have relocated and are uncontactable, a waiver of consent for the clinician to provide de-identified retrospective data has been approved by the Sydney Children's Hospitals Network (SCHN) Ethics Committee in acknowledgment of the public interest imperative to understand the impact of prolonged detention on Nauru in children and adolescents.

PARTICIPANT WITHDRAWAL AND LOSS TO FOLLOW-UP

If a participant or their parent/legal guardian wishes to withdraw from the study, data will be withdrawn from the full data set to meet the individual's wishes. All major issues arising from this study will be reported to the SCHN Ethics Committee and compiled in a final study report with reasons for the issue arising, including participant withdrawal and revocation of consent. The proportion of participant withdrawals and loss to follow-up will be recorded and reported and is of particular interest given the underlying health and well-being vulnerabilities of this cohort.

ETHICS AND DISSEMINATION

Ethical approval together with the site specific approvals covers 11 participating sites where eligible study children and adolescents have had or will have health assessments.

In order to ensure dissemination of this research is relevant and sensitive to the needs of this cohort, our core research team includes an asylum seeker (RR) who has spent time in Australian immigration detention.

METHODOLOGICAL CONSIDERATIONS

Practical and ethical obstacles to research with detained people in a politicised context include access restrictions, uncertainty of the nature of informed consent and the validity or adequacy of standardised measures within this culturally and linguistically diverse cohort. Accessing a suitable or 'generalisable' cohort is almost impossible given the changing nature of refugee populations, multiple relocations and difficulties in engaging people whose status is uncertain. In addition, obtaining informed consent remains a challenge given that some may perceive participation in research as a threat to achieving positive refugee determinations. These challenges are compounded with children.

Although many of the measurement instruments are not well validated in refugee populations, standard measures are important for gathering replicable evidence. In our study we used the measurement instruments most commonly used in the relevant literature for comparative purposes, including PTSD measures, R-ACE, ACE and the SDQ.^{22 33 40–42}

There is ongoing debate about how to quantify the impact of refugee children's exposure to different kinds of stress and trauma over the course of displacement, flight and resettlement, particularly when arrival in a potential host country has been followed by prolonged detention. Dissecting out the impact of multiple events operating at the child, family, settlement and societal level and their relative impact on health and well-being is complex. This necessitates long-term follow-up with collection of data on multiple risk and protective factors.

While the validity of a study examining the impact of detention without a non-detained control group can be questioned, we argue that there are several recent or current Australian studies of refugee population that can be used for comparative purposes without incurring the costs of recruiting a control group. These involve children and adolescents who have not been detained and include (i) the Western Australian longitudinal study (involving 204 and 143 patients aged 2 to 16 years) over 2014 to 2016 with 6-month follow-up with SDQ and R-ACE; (ii) an adolescent study from Melbourne, Australia, which assessed the predictors of self-reported health and happiness among 120 refugees over their first 8 years of resettlement (2004 to 2013)^{23 43} and (iii) the Australian Government Building a New Life in Australia involving 2399 recently-arrived refugees (including 135 adolescents aged 15 to 17 years) from their early months

in Australia to their eligibility for citizenship.⁴⁴ The latter study demonstrated that 3 years post-arrival, the presence of either one or both parents with persistently high PTSD symptoms was associated with children having greater emotional difficulties and poorer overall psychosocial adjustment (using the SDQ).^{44 45} Parental well-being is therefore measured in our study.

Cohort children are likely to have been, and continue to be, exposed to a range of interventions following arrival in Australia. We support that children access medical care, counselling and services that address the social determinants of health. In order to measure these interventions and their potential impact on health and well-being outcomes, we will collect detailed data on access to healthcare and interventions conducted at each study contact. Data analysis will attempt to assess the extent to which these affect health and well-being outcomes.

To conduct the required research in an ethical manner can be prohibitively costly as face-to-face interpreters are often required, interventions for children and families with identified problems need to be provided and tracking participants is resource intensive.^{5 9 46–48} The willingness of involved clinicians to undertake this research at each of their sites without additional resources is testament to their commitment to influencing policy change to protect the health and well-being of children and adolescents seeking asylum in Australia.

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Contributors Study authors for this research include the core research study team, who will be responsible for collating, analysing and writing up the data and the lead clinician at each of the 11 sites across the country. Conceptualisation of this protocol: KZ, LS, NS, NH, RR, RL (core study team). Methodology, drafting, revisions and final approval: KZ, LS, NS, NH, RL, RA, JC, SC, JF, HG, DI, DL, PL, RM, SM, CN, LN, SR, HY.

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Competing interests Nil

Patient consent for publication Not required.

Ethics approval Ethical approval has been granted for this research study by the Sydney Children's Hospitals Network Human Research Ethics Committee (HREC reference 2019/ETH11723).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing is not applicable as no data sets have been generated and/or analysed for this study as yet as this is a protocol.

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