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BMJ Paediatrics Open

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

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Keywords:	Comm Child Health, Health services research, Neurodevelopment, General Paediatrics

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

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Key words

Comm Child Health, Health services research, Neurodevelopment, General Paediatrics

Word count – 2498 excluding title page, abstract, references, what is known/this study adds.

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Abstract

Introduction: Immigration detention has a profound and negative impact on the physical health, mental health, development and social-emotional wellbeing of children, adolescents and their family. Australian clinicians will report results from detailed health and wellbeing 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 wellbeing 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 five year follow-up period. Measures include demographics, residency and detention history, other social risk and protective factors for health and wellbeing (e.g. adverse childhood experiences), physical health and wellbeing outcomes (including mental health, development and social-emotional wellbeing) and clinical service utilisation. Longitudinal follow-up will include a combination of retrospective and prospective data collection to capture outcomes over a 5 year period after arrival in Australia. Analysis will be undertaken to explore baseline factors, with regression analyses to assess their impact on health and wellbeing outcomes. To understand how children's outcomes change over time, multi-level 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 were sought from 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.

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What is known about the subject

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

What this article adds

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

Introduction

There are an estimated 70.9 million forcibly displaced people worldwide, the highest level on record; over half of these are children and adolescents (1). Displaced children, adolescents and adults face multiple physical and mental challenges pre-migration, in transit and continuing hardships post-migration (2, 3). Many countries detain asylum seekers while they process their asylum application. International literature exists pertaining to the profound negative impact of detention on physical health, mental health and wellbeing in children, adolescents and adults (3-10). The severity of mental distress increases 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 (4).

Australia has a formal refugee intake program, accepting between 12,000 – 20,000 refugees under the Humanitarian Entrants Program after their claims are processed by the United Nations High Commissioner for Refugees (UNHCR) overseas. This program supports refugees with housing, case management, English language lessons, public school enrolment, social security payments and access to the universal healthcare system, including reduced price pharmaceutical benefits, consistent with other Australian citizens and permanent residents (11). In contrast, Australia has a punitive policy of deterrence for people applying for refugee status once in Australia, or ‘asylum seekers’, particularly those arriving by boat. Australia’s immigration detention policies are one of the most punitive in the world and they violate human rights obligations under the International Covenant on Civil and Political Rights and the Convention on the Rights of the Child (10). Since 1992 all asylum seekers have been subjected to mandatory detention and, from 2013, all boat arrivals have been processed offshore on remote islands such as Nauru (adults and children) and Manus Island (only adults). All children and their families were released from offshore detention on Nauru by early 2019, by which time many had been living in harsh physical and psychological conditions for more than 5 years (5). The detention is unprecedented and the duration prolonged. The extent of the negative effects on physical and mental health for the immediate and longer term is unknown.

A longitudinal study of these children and adolescents will enable tracking of their physical health, mental health, development and social-emotional wellbeing over time. Importantly, this objective and structured follow up may also assist in early identification of those in need of intervention. There are many practical and political challenges to working with this cohort of children, but Australia is unfortunately in a unique position to document in detail the physical health and wellbeing of asylum seeking children who have in immigration detention for prolonged periods. Paediatricians and child psychiatrists across Australia who specialise in refugee health are part of an organised network, known as the ‘Australian Refugee Child Health Network (ARCH)’, and provide evidence-based care to the majority of children that were detained on Nauru. This expert care was delivered as telehealth consultations prior to transfer, comprehensive medical assessments on arrival and ongoing clinical reviews.

It is estimated that around 200 children detained on Nauru between 2013 and 2019 and many clinicians who performed their medical assessments have agreed to be co-investigators on this study. Understanding the immediate and longer-term impact of detention may allow us to mitigate harm through sharing this knowledge with international colleagues providing

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3 health care to children and adolescents who have been detained, as well as inform policy
4 nationally and internationally.
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6 **Methods and analysis**

7 **Design**

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10 This is a longitudinal study of children and adolescents who were detained in Australian
11 offshore detention. We will combine retrospective and prospective methods to describe their
12 physical health, mental health, development, social and emotional wellbeing at baseline (prior
13 to transfer or on arrival in Australia) and over a 5 year follow up period after transfer to
14 Australia. Retrospective data will be extracted from existing medical records, and
15 prospective follow up will involve providing data from annual consultations for a period of 5
16 years post-arrival in Australia. Follow up will incorporate standardised assessments of social
17 and emotional wellbeing using the Strengths and Difficulties Questionnaire (SDQ). These
18 data will be collected using a Research Electronic Data Capture (REDCap) survey completed
19 by the patient's clinician.
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25 **Participants**

26 Children and adolescents (younger than 18 years at the time of initial immigration detention)
27 who were in immigration detention or offshore processing on Nauru and received a clinical
28 consultation prior to, or on arrival in Australia, will be eligible for this study. Approximately
29 200 children were transferred from Nauru between 2013 and 2019. The clinician
30 investigators from the Australian Refugee Child Health Network will identify eligible
31 participants and invite them and/or their legal parent/guardian to participate.
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35 **Measures**

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37 Measures that will be collected are demographics (including residency history and visa
38 status), psychosocial risk and protective factors, physical health and clinical characteristics.
39 The key outcome measure of interest is wellbeing, including mental health, development and
40 social-emotional wellbeing. Baseline data collection will include all measures, whereas
41 annual follow up data will not include measures that do not change over time. For prospective
42 follow up data, clinicians will be asked to use standardised questions for the assessment of
43 their patient's mental health (such as the Child Stress Disorders Checklist for PTSD), and
44 standardised tools for social-emotional wellbeing (the Strengths and Difficulties
45 Questionnaire).
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49 **1. Demographics**

50 Demographic details include the child's date of birth, gender, place of birth, ethnic
51 background, country of origin, country of transit, primary language spoken, date of arrival in
52 Australia, and family composition. Residency history and visa details include the initial date
53 of detention, total time in detention, the number of times and places of detention and current
54 visa type.
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57 **2. Psychosocial risk and protective factors**

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3 These include known or suspected risk and protective settlement factors, categorised into
4 child, family and settlement factors. This information is often collected as part of routine
5 medical consultations for refugee children. It includes Refugee specific Adverse Childhood
6 Experiences such as prolonged transit and witnessing trauma (R-ACE) (12), as well as the
7 standard Adverse Childhood Experience (ACE) measures, such as psychological, physical
8 and sexual abuse and household dysfunction (substance abuse, mental illness, mother treated
9 violently and criminal behaviour in the household) (13). Scoring for the ACE is based on the
10 sum of childhood abuse and household dysfunction categories, with a score of 0 indicating no
11 exposure, and a score of 7 indicating exposure to all categories (13).
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14 15 **3. Physical health and clinical characteristics**

16
17 This includes diagnoses coded according to the Australian Modification of the International
18 Statistical Classification of Diseases and Related Health Problems (ICD-10-AM), an
19 expanded version of the World Health Organization (WHO) ICD-10. Additional physical
20 health measures include height, weight, body mass index, immunisation status, oral health,
21 medication and other treatments. Clinical characteristics include who performed the health
22 assessments, their frequency and location, and length of stay if inpatient admission was
23 required.
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26 27 **4. Outcome measure: Wellbeing**

28 Wellbeing outcomes are categorised into medical and mental health diagnoses,
29 developmental difficulties or disabilities, and social-emotional wellbeing.
30

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32 Formal mental health diagnoses will be categorised by ICD-10-AM codes. In order to capture
33 sub-diagnostic symptoms, as not all mental health symptoms experienced by children and
34 adolescents reach the threshold for a DSM V diagnosis, mental health symptoms will be
35 dichotomously coded as 'yes' or 'no'. This includes Pervasive Refusal Syndrome (PRS)
36 symptoms (14) and Post Traumatic Stress Disorder (PTSD) symptoms (15).
37

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39 Developmental difficulties or disabilities will be categorised by age (pre-school and school
40 aged children/adolescents). Clinicians will report on any developmental delay, regression,
41 learning difficulties, Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum
42 Disorder (ASD) and others. If neither screening nor formal assessment was undertaken,
43 clinicians will provide a clinical impression of their patient's neurodevelopmental status.
44

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46 The Strengths and Difficulties Questionnaire (SDQ) will be used to measure social-emotional
47 wellbeing. The SDQ includes 25 items, with five symptom subscales assessing emotional
48 symptoms, conduct problems, hyperactivity and inattention, peer relations, and prosocial
49 behaviour (16, 17).
50

51 52 **Data collection and storage**

53 All data will be collected electronically, using Research Electronic Data Capture (REDCap)
54 survey tool, managed by the study team in Sydney. REDCap is a secure web-based
55 application used to support data collection for research studies (18).
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58 Clinicians will receive an email from the research team containing the unique study
59 identification numbers for their patients only, and an online link to a REDCap survey for
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entering data. Clinicians will then enter data from the patient's medical records that will then be sent to the research team for analysis.

Data analyses

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 wellbeing conditions. Length of stay and other parameters of admission will be analysed and presented. Follow-up data will include community or held residential detention, relocated or lost to follow-up. Outcomes of interest will include social-emotional wellbeing as measured using the SDQ, Pervasive Refusal Syndrome symptoms at baseline and mental health disorders.

Descriptive analyses will be undertaken to summarise means, variances, and distributions of baseline factors. Regression analysis will be conducted to examine how baseline factors influence children's outcomes assessed at follow-up periods. To understand how children's outcomes change over time, multi-level regression analysis (e.g. latent growth curve analysis) will be utilised to quantify the pattern of change in these outcomes. We will examine how baseline factors and factors that vary with time shape children's outcome trajectories. Non-parametric measures as appropriate and structural equation modelling will be conducted to explore the inter-correlation between baseline factors, mediational factors, and outcomes (e.g. mental health problems) to assess trajectories over time.

Data storage

Participant identification numbers and contact details will be stored electronically in a password-protected excel spreadsheet in a secure location on UNSW OneDrive, accessible only to the study team named on the protocol. No clinically sensitive data will be stored with this file, which will be stored separately from any data analysis files. All data collected for analysis will be de-identified using the participant's unique identification number. Critical REDCap security components involve user authentication and role-based security. More specifically, the 'User Rights' tool ensures that all survey data entered are confidential and secured with restricted access to certain data from research personnel. Survey forms are also only accessible to users that have been granted survey access privileges.

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

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3 and does not seek to add to their stressors by requesting anything additional from them apart
4 from their/parental consent and attending follow up annually.
5

6 7 **Participant consent and withdrawal**

8 In order to maintain participant confidentiality and privacy, eligible participants and their
9 parent/legal guardian will be invited to participate in the study by their usual clinician, with a
10 qualified health care interpreter as necessary. This will occur at the next scheduled
11 consultation or, where no consultation is scheduled within two months, clinicians will
12 telephone participants and invite them to a consultation for discussion about the study.
13 During this consultation, clinicians will explain what participation will involve, that
14 participation is voluntary, encourage eligible participants to ask any questions they may have
15 and facilitate provision of consent to participate if they are interested. Consent will be
16 sought from both the child/adolescent participant and parent/legal guardian where the
17 clinician deems the child/adolescent able to give informed consent, or from the parent/legal
18 guardian only when the participant is not deemed competent and mature to give informed
19 consent.
20
21

22
23 Clinicians will present the two participation options below to children/adolescents and
24 parents/guardians:
25

26
27 **Participation Option 1. Retrospective follow-up:** Participants consent to clinicians
28 providing data from previous clinical consultations that took place from around the time of
29 transfer to Australia, and up to the date of consent to this study. As this participation option
30 involves already collected data, no additional time commitments are required from
31 participants.
32

33 **Participation Option 2. Retrospective and prospective follow-up:** Participation will
34 involve Option 1 above (retrospective follow-up) PLUS consent to clinicians providing data
35 from medical records of new routine clinical consultations for the next five years. If no
36 routine consultations are clinically required, then participants will be invited by their refugee
37 health clinician to attend an annual physical health and wellbeing assessment that will take
38 approximately one hour.
39

40
41 Where participants have relocated and are uncontactable, a waiver of consent to Participation
42 Option 1 (de-identified retrospective follow-up) has been approved by the Ethics Committee
43 in acknowledgment of the public interest imperative to understand the impact of prolonged
44 detention on Nauru in children and adolescents.
45

46 47 **Participant withdrawal and loss to follow up**

48
49 If a participant or their parent/legal guardian wishes to withdraw from the study, data will be
50 withdrawn from the full dataset to meet the individual's wishes and in compliance with
51 individual circumstances. All major issues arising from this study will be reported to the
52 SCHN ethics committee and compiled in a final study report with reasons for the issue
53 arising, including participant withdrawal and revocation of consent. The proportion of
54 participant withdrawals and loss to follow-up will be recorded and reported and is of
55 particular interest given the underlying health and wellbeing vulnerabilities of this cohort.
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Ethics and dissemination

Ethical approval has been granted for this research study by the Sydney Children's Hospitals Network Human Research Ethics Committee (HREC reference 2019/ETH11723). Together with the Site Specific Approvals (SSA), this covers all participating sites where eligible study children and adolescents have had or will have health assessments.

In order to ensure the conceptualisation, methodology, interpretation and 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.

Funding:

This is an unfunded study and investigators have agreed to contribute their time in kind.

Competing interests: nil

Author contributions

Conceptualisation: 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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Keywords:	Comm Child Health, Health services research, Neurodevelopment, General Paediatrics

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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 wellbeing of children, adolescents and their families. Australian clinicians will report results from detailed health and wellbeing 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 wellbeing 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 five year follow-up period. Measures include demographics, residency history and refugee status, physical health and wellbeing outcomes (including mental health, development and social-emotional wellbeing), clinical service utilisation and psychosocial risk and protective factors for health and wellbeing (e.g. 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 wellbeing outcomes. To understand how children's outcomes change over time, multi-level 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 five of the eleven 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.

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3 **What is known about the subject**
4

- 5
6 1. The number of forcibly displaced people worldwide is the highest on record and over
7 half of these are children and adolescents.
8 2. The health and wellbeing of asylum seeking children and adolescents is a major
9 global public health concern.
10 3. Immigration detention is known to have a negative impact on children and
11 adolescents' mental health, physical health, development, social and emotional
12 wellbeing.
13

14
15 **What this article adds**
16

- 17 1. This protocol describes the methods to undertake a longitudinal cohort study of
18 children and adolescents who have been detained in immigration detention.
19 2. We will document the immediate and long-term physical health, mental health,
20 development and social-emotional wellbeing of children and adolescents who have
21 experienced prolonged detention.
22 3. Understanding the immediate and long-term impact of detention may allow us to
23 mitigate harm by informing policy nationally and internationally.
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Introduction

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 Nations High Commissioner for Refugees (UNHCR) manages programs to resettle people whose claim for refugee status has been recognized 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 program accepting 12,000 – 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, health care, 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 wellbeing 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-

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3 28). Practices in the reception country have the potential to reduce cumulative risk and
4 enhance protective factors to positively influence health and wellbeing outcomes. (2, 4, 23,
5 29).
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8 Only one study has undertaken a comparison of the mental health of resettled refugee
9 children who were not detained with those who were held in closed detention (30). This
10 cross-sectional study demonstrated that children with similar pre-arrival adversity and
11 detained on Christmas Island, another processing centre for Australia, had worse social-
12 emotional wellbeing outcomes than children not detained (30). There is a dearth of
13 appropriately designed longitudinal studies in the literature documenting the long term
14 impact of immigration detention in children. This is of global importance given the potential
15 to avert the developmental and long term consequences (31).
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20 Objectives

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

37 38 39 **Study design**

40
41 This is a longitudinal study of children and adolescents who were detained in Australian
42 offshore detention. We will describe their physical health, mental health, development, social
43 and emotional wellbeing at baseline (prior to transfer or on arrival in Australia) and over a 5
44 year follow up period after transfer to Australia. Retrospective data will be extracted from
45 existing medical records, and participants’ health and wellbeing will be tracked at annual
46 consultations for 5 years post-arrival in Australia. Follow up will incorporate usual clinical
47 assessment, an interview schedule and standardised assessments of social and emotional
48 wellbeing.
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52 **Setting and study sample**

53 **Participants**

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

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, 32). Conditions included overwhelming heat, overcrowded tents and close proximity to open-pit phosphate mining, creating 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, 32).

Publicly accessible data is mostly available for both Nauru and PNG combined. Since 2012, 4,177 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, 1,117 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, 33).

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 wellbeing, including mental health, development and social-emotional wellbeing. 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 wellbeing.

1. 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.

2. 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, such as prolonged transit, interrupted education and witnessing trauma (R-ACE) (34), as well as the standard Adverse Childhood Experience (ACE) measures, such as psychological, physical

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3 and sexual abuse and household dysfunction (substance abuse, parental mental illness,
4 mother treated violently and criminal behaviour in the household) (31). Scoring for the ACE
5 is based on the sum of childhood abuse and household dysfunction categories, with a score of
6 0 indicating no exposure, and a score of 7 indicating exposure to all categories (31).
7

8 9 **3. Physical health and clinical characteristics**

10
11 Diagnoses will be coded according to the Australian Modification of the International
12 Statistical Classification of Diseases and Related Health Problems (ICD-10-AM), an
13 expanded version of the World Health Organization (WHO) ICD-10. Additional physical
14 health measures include height, weight, body mass index, immunisation status, oral health,
15 medication and other treatments. Clinical characteristics include who performed the health
16 assessments, their frequency and location, access to healthcare and length of stay if inpatient
17 admission was required.
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20 21 **4. Outcome measure: Wellbeing**

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23 Wellbeing outcomes are categorised into medical and mental health diagnoses,
24 developmental difficulties or disabilities, and social-emotional wellbeing.
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26
27 As not all mental health symptoms experienced by children and adolescents reach the
28 threshold for a DSM V diagnosis, sub-diagnostic mental health symptoms will be
29 dichotomously coded as 'yes' or 'no'. This includes Pervasive Refusal Syndrome (PRS)
30 symptoms (35) and Post Traumatic Stress Disorder (PTSD) symptoms (36).
31

32
33 Developmental difficulties or disabilities will be categorised by age (pre-school and school
34 aged children/adolescents). Clinicians will report on developmental delay, regression,
35 learning difficulties, Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum
36 Disorder (ASD) and others. If neither screening nor formal assessment was undertaken,
37 clinicians will provide a clinical impression of their patient's neurodevelopmental status.
38

39
40 The SDQ will be used to measure social-emotional wellbeing and includes 25 items, with
41 five symptom subscales assessing emotional symptoms, conduct problems, hyperactivity and
42 inattention, peer relations, and prosocial behaviour (37, 38).
43

44 **Data sources and storage**

45 **Data storage**

46
47 Data will be collected using a Research Electronic Data Capture (REDCap) survey, a secure
48 web-based application to support research data collection (39). Critical REDCap security
49 components involve user authentication and role-based security to ensure that all survey data
50 entered are confidential and secured with restricted access to research personnel. Sensitive
51 identifying information will be stored separately from any data analysis files in a secure
52 location on UNSW OneDrive, accessible only to the study team.
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55 **Statistical methods**

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58 Data will be analysed in a de-identified format. Data analyses will demonstrate the proportion
59 of participants who were diagnosed with a range of medical, mental health, developmental or
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3 social-emotional wellbeing conditions at baseline and follow-up. Follow-up data will include
4 community or held residential detention, relocated or lost to follow-up. Outcomes of interest
5 will include social-emotional wellbeing, and mental health symptoms and disorders.
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7
8 Descriptive analyses will be undertaken to summarise means, variances, and distributions of
9 risk and protective factors at baseline and follow-up. Causal models will be developed to
10 consider the complex relationships to physical and mental health outcomes. Structural
11 equation modelling will be used to explore the causal relationships between predictors,
12 mediational factors, and outcomes (e.g. mental health problems). Latent growth curve
13 analysis will be utilised to examine the pattern of change in these outcomes over time.
14
15

16 **Patient and Public Involvement Statement**

17
18 One of our core research study team (RR) has lived experience of detention as an asylum
19 seeker in Australia, and in this way is similar to our patient cohort. He was involved in the
20 study from the beginning, providing advice on key aspects of the study design, including the
21 definition of the research questions, choice of the outcome measures and selection of relevant
22 questions for the questionnaire. He will be involved in write-up and public dissemination of
23 any research outputs.
24
25

26
27 Although we as authors support active involvement of patients as co-producers of research,
28 we did not involve patients in this particular study. We considered patient involvement as
29 inappropriate given that our patients are children and adolescents who have experienced
30 prolonged detention in Australia's offshore processing system and whose immigration status
31 remains uncertain. This project involves the collection of their data from their treating teams
32 and does not seek to add to their stressors by requesting anything additional from them apart
33 from consent and attending follow up annually.
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36 **Participant consent and withdrawal**

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38 In order to maintain participant confidentiality and privacy, eligible participants and their
39 parent/legal guardian will be invited to participate in the study by their usual clinician. This
40 will occur at the next scheduled consultation or, where no consultation is scheduled within
41 two months, clinicians will telephone participants and invite them to a consultation for
42 discussion about the study. During this consultation, clinicians will explain what participation
43 will involve, that participation is voluntary, encourage eligible participants to ask any
44 questions they may have and facilitate provision of consent to participate if they are
45 interested. A qualified health care interpreter using participants' preferred language will be
46 used to promote informed consent. Consent will be sought from both the child/adolescent
47 participant and parent/legal guardian where the clinician deems the child/adolescent able to
48 give informed consent, or from the parent/legal guardian only when the participant is not
49 deemed competent and mature to give informed consent. Participants who reach the age of 18
50 years will be able to give their own consent (40).
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54 Clinicians will present the two participation options below to children/adolescents and
55 parents/guardians:
56

57 **Participation Option 1. Retrospective:** Participants consent to clinicians providing data
58 from previous clinical consultations that took place from around the time of transfer to
59 Australia, and up to the date of consent to this study. As this participation option involves
60 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 five years. If no routine consultations are clinically required, then participants will be invited to attend an annual health and wellbeing assessment that will take approximately one 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 dataset 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 wellbeing vulnerabilities of this cohort.

Ethics and dissemination

Ethical approval has been granted for this research study by the SCHN Human Research Ethics Committee (HREC reference 2019/ETH11723). Together with the Site Specific Approvals (SSA), this covers eleven 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, 34, 41-43).

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,

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3 particularly when arrival in a potential host country has been followed by prolonged
4 detention. Dissecting out the impact of multiple events operating at the child, family,
5 settlement and societal level and their relative impact on health and wellbeing is complex.
6 This necessitates long-term follow up with collection of data on multiple risk and protective
7 factors.
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10 Whilst the validity of a study examining the impact of detention without a non-detained
11 control group can be questioned, we argue that there are several recent or current Australian
12 studies of refugee population that can be used for comparative purposes without incurring the
13 costs of recruiting a control group. These involve children and adolescents who have not been
14 detained and include (i) the Western Australian longitudinal study (involving 204 and 143
15 patients aged 2-16 years) over 2014-2016 with 6 month follow-up with SDQ and R-ACE; (ii)
16 an adolescent study from Melbourne, Australia, which assessed the predictors of self-reported
17 health and happiness among 120 refugees over their first eight years of resettlement (2004-
18 2013) (23, 44) and (iii) the Australian Government Building a New Life in Australia (BNLA)
19 involving 2,399 recently-arrived refugees (including 135 adolescents aged 15-17 years) from
20 their early months in Australia to their eligibility for citizenship (45). The latter study
21 demonstrated that 3 years post arrival, the presence of either one or both parents with
22 persistently high PTSD symptoms was associated with children having greater emotional
23 difficulties and poorer overall psychosocial adjustment (using the SDQ) (45, 46). Parental
24 wellbeing is therefore measured in our study.
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28 Cohort children are likely to have been, and continue to be, exposed to a range of
29 interventions following arrival in Australia. We support that children access medical care,
30 counselling and services that address the social determinants of health. In order to measure
31 these interventions and their potential impact on health and wellbeing outcomes, we will
32 collect detailed data on access to healthcare and interventions conducted at each study
33 contact. Data analysis will attempt to assess the extent to which these affect health and
34 wellbeing outcomes.
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38 To conduct the required research in an ethical manner can be prohibitively costly as face-to-
39 face interpreters are often required, interventions for children and families with identified
40 problems need to be provided, and tracking participants is resource intensive (5, 9, 47-49).
41 The willingness of involved clinicians to undertake this research at each of their sites without
42 additional resources is testament to their commitment to influencing policy change to protect
43 the health and wellbeing of children and adolescents seeking asylum in Australia.
44

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46 This is currently an unfunded study and investigators have agreed to contribute their time in
47 kind. We intend to apply for funding once all eleven site-specific ethical applications have
48 been approved.
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50 **Competing interests:** nil

51 **Author contributions**

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56 Study authors for this research include the core research study team, who will be responsible
57 for collating, analysing and writing up the data, and the lead clinician at each of the 11 sites
58 across the country. Conceptualisation of this protocol: KZ, LS, NS, NH, RR, RL (core study
59 team)
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3 Methodology, drafting, revisions and final approval: KZ, LS, NS, NH, RL, RA, JC, SC, JF,
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