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Longitudinal cohort: health and wellbeing of refugee children in a regional community - methods and sample representativeness, recruitment and retention

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5 6	2	Longitudinal cohort: health and wellbeing of refugee children in a regional
7 8	3	community - methods and sample representativeness, recruitment and retention
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2 3 4	39	Abstract
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41 42 43	56	Findings to date
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49 50	59	representation of
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Purpose: Few studies explore the long term health and wellbeing of refugee
children. A cohort of refugee children was created to determine health and wellbeing
outcomes over time. This article describes the methodology used to conduct a
longitudinal cohort study in refugee children in a regional community, including
sample characteristics and effectiveness of recruitment and retention strategies.
Participants: Newly arrived refugee children settling in regional part of Australia and
aged up to 15 years were recruited between 2009 and 2013 and followed for three
years.

examinations shortly after arrival consistent with routine care. At Years 2 and 3 of
follow up, additional surveillance was conducted by the research team. Preschool
children had developmental and school-aged children had social-emotional
screening assessments. Families were assessed for risk and protective factors,
classified into child, family and settlement factors, using a structured interview and
the Social Readjustment Ratings Scale (SRRS). Participant experience of the
research was explored.

Findings to date: Eligibility criteria were met by 158 of 228 (69%) newly arrived
children, 61 of whom (39%) were enrolled. Retention was 100% (n=61) at Year 2
and 85% at Year 3. The study sample was younger than and had an over-

59 representation of African refugees as compared to the eligible population. Parents

- ⁶⁰ reported that the research was respectful and the questionnaires easy to answer.
- **Future plans:** This study demonstrates that a longitudinal cohort study in a refugee
- 62 child population is feasible and acceptable, and retention rates can be high. The

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63	establishment of this cohort provides the opportunity to gather valuable data about
64	the early settlement experience, risk and protective factors and long term health and
65	wellbeing outcomes in refugee children. These are necessary to identify refugee
66	children in need of additional support and guide future service delivery.
67	Key Words: Refugee, children, development, cohort, longitudinal, health, wellbeing,
68	Community child health, PAEDIATRICS
69	Strengths and limitations
70	 a strength in the study design was recruitment through an established high
71	uptake population-based screening program for refugees, and utilising trusted
72	nurses to enrol families and provide ongoing care
73	• the study demonstrated feasibility and acceptability in examining a wide range
74	of risk and protective factors and measuring health and wellbeing outcomes
75	over 3 years in a population known to be challenging to follow up
76	a key strength was the consideration of many important factors in conducting
77	ethical research in this highly vulnerable population, creating the potential to
78	add to the evidence base, gather valuable data, and contribute to policy and
79	practice change
80	• we sought to offset an important limitation, small sample size, by investing in
81	retention strategies to minimise attrition, which were effective once
82	participants were recruited
83	limited availability of professional health care interpreters was a key challenge
84	in recruitment and the need for interpreters also increased the length of
85	assessment time and study costs
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Introduction [4085 words]
Australia accepts around 13 000 – 20 000 refugees per year under the humanitarian
program, with 40 to 50% of these entrants being children and young people. (1)
Children from a refugee background often arrive in Australia with unmet health
needs due to a combination of factors including forced migration, suboptimal living
conditions and limited access to healthcare. (2,3) Routine screening on arrival
detects many significant and treatable, but often occult, health problems such as
infectious diseases, nutritional deficiencies or incomplete immunisations. (4-8) The
Royal Australasian College of Physicians (RACP) therefore strongly advocates
health screening for refugees but the need for routine assessments of developmental
or social-emotional wellbeing has not been formally examined in cross sectional or
prospective studies. (9,10)
A child's development is a complex dynamic interplay between biological, social,
environmental and behavioural factors. (11) Early developmental problems are
associated with increased risk of subsequent school failure, teenage pregnancy,
unemployment and imprisonment but directed early intervention can improve
developmental outcomes. (12-14) Refugee children are at particularly risk of adverse
outcomes because of the refugee experience itself and the process of resettlement.
(15-17)
Refugee children have an increased risk of mental illnesses such as depression and
anxiety but they also demonstrate resiliency and good social adjustment. (18-22)
Evidence suggests that peer relationships and connections to familiar communities
are important in social adjustment. (23) The role of other factors such as parental
education, employment, single parent status, access to health care, family stressors,
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community support and exposure to racism are likely to influence developmental and
 social-emotional outcomes in refugee children but there is limited research in this
 area. (24-30)

Prospective studies are advantageous in that they allow researchers to track individual children over time, thereby reducing recall bias associated with retrospective studies. They can gather information on risk and protective factors associated with key outcomes, and thus identify children at higher risk of poor outcomes. (31-33)

Research in refugee children presents multiple challenges, including (1) access to a suitable cohort; (2) language and cultural barriers; (3) lack of cross-cultural validation of standardised screening tools; and (4) working with vulnerable children and families, including parental concerns about research participation. Furthermore, long-term follow-up and interpreter costs make such research expensive to undertake in an ethical manner. These challenges have led to systematic exclusion of refugee children from key longitudinal research studies in Australia. (34,35) The Longitudinal Study of Australian Children (LSAC) does not include sufficient refugee children to allow identification of their specific needs and the Longitudinal Survey of Immigrants to Australia (LSIA) focuses on adult immigrants as the primary participants. (34,35) One study of 97 refugee youth settling in Australia achieved follow up for 3 years and identified perceived discrimination as a key determinant of self-rated wellbeing. (33)

Research questions

The research questions this study seeks to explore are how refugee children are
tracking over time, particularly in relation to their development and social-emotional
wellbeing, and risk and protective factors associated with these outcomes.

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6 7	135	
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9	136	Purpose
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11 12	107	A cohort of refugee children was created to investigate the physical health,
13	137	A conort of refugee children was created to investigate the physical health,
14	138	development and social-emotional wellbeing in refugee children and the impact of
15 16		
17	139	risk and protective factors on these outcomes over their first 3 years in Australia.
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19	140	This article describes the methodology used to conduct a longitudinal cohort study in
20 21	141	refugee children in a regional community, including sample characteristics, and
22	111	rolagee entaren in a regional community, meraanig earripte entaractionetice, and
23	142	recruitment and retention strategies and their effectiveness.
24 25		
26	143	Methods and design
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28 29		
30	144	Setting
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32 33	145	The Illawarra region of New South Wales (NSW), Australia, has a long history of
33 34	146	refugee resettlement including European communities following World War II, the
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36	147	Vietnamese community in the 1970s and the Serbian, Croatian and Bosnian
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39	148	communities in the 1990s. The most recent arrivals are from African countries,
40	149	Burma and the Middle East. (1) In this region, a collaborative nurse-led community
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43	150	based model of care has been in place since 2007. This model operates through
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45 46	151	settlement services, which link new arrivals with a network of local refugee-friendly
47	152	general practitioners (GPs), who provide initial health screening and ongoing family-
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49 50	153	centred care. Refugee Health Nurses (RHNs) provide support to GPs and ensure
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52	154	health needs are addressed. Specialist health services provide training forums,
53 54	165	screening and management guidelines, access to rapid tertiary-level consultative
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56	156	expertise, and specialised Refugee Health Clinics. This collaborative model of care
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has been shown to be successful in undertaking physical health screening of the
entire population (100%) of newly arrived refugee children settling in the region.
(36,37)

Recruitment and participants

Subjects were recruited into the study through the existing model of care described and building on the established relationships with refugee communities and health professionals working with them. Eligible subjects were children aged up to 15 years of age, who arrived in Australia on permanent humanitarian visas between May 2009 and April 2013, and settled within the regional catchment area of the Illawarra Shoalhaven Local Health District. A continuous recruitment strategy was employed to maximise the number of study participants. The Refugee Health Nurses (RHNs) were chosen as the primary research assistants because they were respected and trusted by settlement services and community members. The RHNs also provided a safety net for this vulnerable population because they were skilled in referring children and families to the complex network of settlement and mainstream health services available. The RHNs approached families with information about the study during routine home visits soon after arrival. Parents were asked permission to be contacted within six to twelve months to further discuss their participation in the research. The research RHN then visited the family to gain formal informed consent and arrange follow-up assessments. All interactions, apart from administrative telephone calls, were conducted with a face to face professional health care interpreter present. (Figure 1)

180 Measurement schedule

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181 Before finalising the measurement schedule, we conducted a small pilot study in 3 182 families to ensure that tools and questionnaires were practical. Based on these assessments and participant feedback, a few questions were altered, repetitive 183 questions were removed and the study measurement instruments were reduced in 184 number to limit questionnaire completion and assessment at each time point to 8 185 186 hours for each child. We also developed a recruitment strategy of preferentially 187 recruiting the youngest two children in each family as including more children 188 created a heavy respondent burden for the family.

The final measurement schedules was as follows: General Practitioners conducted 189 190 the physical health examinations and pathology testing on all children shortly after 191 arrival (average 20.4 days; range 6 to 98 days), consistent with the model of care 192 (within the first year; Year 1 assessments). Research assessments were carried out 193 by the research team, which included the Refugee Health Nurse and paediatric doctors. The first follow-up assessment occurred at Year 2 (average 12.5 months 194 195 after arrival; range of 6-23 months) and the second follow-up assessment at Year 3 196 (average 30.6 months after arrival; range of 21-40 months). Developmental and 197 social-emotional screening assessments were delayed until Years 2 and 3 to allow for a period of adjustment and to reduce capturing immediate resettlement stress. 198 199 At Years 2 and 3 the preschool children (6 months to 5 years old) had developmental screening assessments using the Australian Developmental Screening Tool (ADST): 200 201 the school-aged children (4-17 years) had social-emotional screening assessments 202 using the Strengths and Difficulties Questionnaire (SDQ). (38,39) Key outcomes for 203 the study were physical health, child development (ADST) and social-emotional 204 health (SDQ) (Table 1).

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All families were assessed for risk and protective factors using a structured interview, which included questions on their experience of participating in the research, and the Social Readjustment Ratings Scale (SRRS). (40) In keeping with the bio-ecological model of child health risk and protective factors were classified into: (i) child factors (age, gender, physical health on arrival), (ii) family factors (family composition, parental disclosure of trauma, time in refugee camp, region of origin) and (iii) settlement factors (stressful life events in last year, employment and study status, English language proficiency, socio-economic resources, experience of discrimination and access to health care) (Table 2). (11) Children who scored in the abnormal or borderline ranges on the developmental or social-emotional screening assessments were referred to the local Refugee Child Health clinical team or their GP.

Measurement instruments

1. Physical Health Assessment

The initial clinical evaluation included a history and examination, screening tests and anthropometric measurements (height, weight and body mass index (BMI)) (Table 1). A schistosomiasis IgG ratio of <0.7 and a strongyloides IgG ratio of <0.8 were considered negative. Malaria screening comprised a thin smear, thick smear and a rapid antigen test. All children had tuberculosis screening using an interferon-y release assay, QuantiFERON TB Gold (QFN). Low ferritin levels (normal: 20-200 micrograms/litre) were used as a marker of iron deficiency. Vitamin D levels were defined as follows: toxicity >250nmol/L; sufficiency 50-230nmol/L; mild deficiency 26-50nmol/L; moderate deficiency 12.5-25nmol/L and severe deficiency

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<12.5nmol/L. (3) Anthropometric measurements were repeated at Year 2 and Year
3.
230 2. Development

231 The Australian Developmental Screening Test (ADST) tool was selected to assess 232 development in preschool children because it was a standardised, individually 233 administered, objective and play-based developmental screening test. (38) The tool 234 assessed five domains of development (language, cognitive skills, fine motor skills, 235 personal/social skills and gross motor skills), and could be administered by any 236 trained health worker over approximately 20 minutes. Using published modified 237 diagnostic criteria, specificity and sensitivity of ADST scores correlate well with the 238 gold standard Griffiths Mental Developmental Scales (GMDS). (41) The ADST 239 domains were scored to produce a developmental age in months and categorised 240 into two possible outcomes: (1) normal and (2) monitor (for children requiring review 241 over time but not necessarily intervention).

3. Social-emotional wellbeing

The parent report version of the Strengths and Difficulties Questionnaire (SDQ) was
used to identify social-emotional problems in children and young people from 4 - 17
years of age. This tool was selected because it has been validated for use across
cultures, was simple and quick to administer and has demonstrated reasonable
cross informant correlations, good internal consistency and correlation with Rutter
scales and the Achenbach Child Behaviour checklist. (20, 42-45)
The SDQ includes 25 items with 5 symptom scales to evaluate emotional symptoms,

- conduct problems, hyperactivity and inattention, peer relations and prosocial
- behaviour. (39) Scores were generated for each subscale and the Total Difficulties

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(TD). High SDQ scores indicate increased risk of social-emotional problems. The
SDQ scores were classified into 3 categories: (1) normal, (2) borderline and (3)
abnormal.

257 4. Risk and protective factors

Risk and protective factors were assessed using a structured interview (Text Box 1) and the Holmes and Rahe Social Readjustment Rating Scale (SRRS) (40). The SRRS was used as a measure of the impact of post settlement life events such as changes in family composition, employment and stability of residence. Scores that were greater than 300 on the scale indicated a high risk (over 80% chance) of developing a significant illness. (41,42) Risk and protective factors were classified into: (i) child factors, (ii) family factors and (iii) settlement factors as described above. (11)

266 Data management

An Access database was developed to capture the data for the study, including
demographic, physical health, child development (ADST) and social-emotional
health (SDQ) data and risk and protective factors. Information was entered by RHNs.
(48)

271 Data Analysis

All data will be analysed using SPSS version 22.0 using a predetermined analysis
plan. (49) Categorical data will be described with frequency percentages and 95%
confidence intervals will be computed using the exact binomial method. P values for
differences in frequency percentages from community norms will be calculated using

a z-test. Within family changes in categorical variables will be assessed using McNemar's test. Continuous data will be described with means and standard deviations (SD) and effect sizes between groups calculated as the mean difference divided by the pooled SD. (50) SDQ scores will be converted to Z-scores using normal population means and compared to a test value of zero using one-sample t-tests. (51) Independent samples t-tests and one-way ANOVA tests will be used to compare mean scores between categorical variables. For non-normally distributed scores, non-parametric equivalents will be used. Pearson's correlation will be used to assess relationships between continuous variables. P values will be considered statistically significant if P<0.05.

286 Findings to date

287 Recruitment and retention

In the 4 year period between May 2009 and April 2013, 86 refugee families arrived in the study region with a total number of 228 children aged under 15 years of age (Figure 1). The eligibility criteria for the study were met by 158 children. The main reason for ineligibility was that two children per family had been enrolled. We approached 85 of the 158 eligible children (54%). Of these, 61 children were recruited for the study (27% of all newly arrived children up to 15 years of age and 39% of all eligible children). There were 38 families with 73 children who were not approached due to lack of available research and interpreting staff (n=52; 71%), families relocating out of the area (n=13; 18%) and inability to contact families (n=8; 11%).

The enrolled sample was similar to the eligible population in terms of gender but the mean age (4 years) was younger than the eligible population (9 years) (Table 1). BMJ Open: first published as 10.1136/bmjopen-2016-011387 on 24 August 2016. Downloaded from http://bmjopen.bmj.com/ on April 16, 2024 by guest. Protected by copyright

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This is consistent with the recruitment strategy of preferentially including the youngest two children in each family. The sample had similar proportions to the eligible population for the Eastern Mediterranean WHO region of origin (21% versus 26% respectively) but the South East Asian region was over-represented (43%) versus 32%) and the African region under-represented (33% versus 42%). This reflected the availability of language specific interpreters available to facilitate recruitment during the study period.

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Primary respondents of the semi-structured interviews were predominantly mothers (n=32; 62%) (Table 3). The majority of parents had received secondary or university level education and around one third were employed in a professional capacity in their country of origin. The corresponding data was not available for the eligible population.

All children (100%) were assessed at Year 2 (n=61). At Year 3, 52 children from 30 families were assessed, which represented a retention rate of 85% The children who were lost to follow-up were similar to the study sample in terms of gender, age, WHO region of origin, language spoken at home and prior education and employment of the primary respondent. Given the importance of maintaining follow-up in this small cohort, a number of strategies to minimise attrition were employed (Text Box 2).

Participant experience:

The study was generally considered acceptable to parents. The majority found the questionnaires easy to answer (Year 2: 33/39, 85%; Year 3: 35/42, 83%) without being confusing (Year 2: 28/39, 72%; Year 3: 43/47, 91%) or raising uncomfortable feelings (Year 2: 37/37, 100%; Year 3: 36/39, 92%), and all parents found the research respectful.

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Ethics approval was provided by the Human Research Ethics Committee Northern Hospitals Network, South Eastern Sydney Illawarra Area Health Service (HREC Ref No 09/163). Informed consent to participate in the study was sought from parents with a professional health care interpreter present.

329 Management of the project

Ethics

The Research Implementation Committee managed the day-to-day operational aspects of the study and met monthly. A Project Management Committee with representatives from each of the partner organisations met quarterly for strategic oversight, reporting and feedback. Policy and implementation agencies are involved and will inform the policy translation phase.

335

336 Discussion

A growing body of research demonstrates that optimising development (including 337 338 language and cognitive development, social-emotional and physical health) in early 339 childhood has positive long term benefits including increasing children's IQ, school 340 achievement, employment, mental health and socio-economic status in adulthood. 341 (52-57) It is this evidence that drives the need to identify those children in need of 342 additional support as early as possible and to design appropriate screening programs and early intervention services. Children from a refugee background are 343 often exposed to significant levels of trauma and instability during the early years 344 345 which increases their risk of poor developmental and social-emotional health 346 outcomes. (58-63) This longitudinal cohort study was designed to utilise an existing

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high uptake model of care to access the newly arrived refugee population to
measure health and wellbeing outcomes and examine a wide range of risk and
protective factors.

The study design described demonstrated commitment by the research team to conduct research in vulnerable communities as suggested by the Australian National Health and Medical Research Council (NHMRC). Recommendations include that such research be descriptive in nature, longitudinal in design, collect evidence to effect change and are underpinned by an ethical theoretical framework that guides design and implementation to produce robust data on health and wellbeing. (64-66) Prospective studies provide invaluable insight on the progression of health over time but present a number of logistic difficulties. Recruitment was anticipated to be a challenge in establishing this cohort and was indeed low at 39% of eligible children. The main obstacle to recruitment was interpreter availability rather than participant

360 refusal, which occurred in only 15% of those approached.

Research in refugee populations may present specific challenges but is crucial to ensure that services are evidence based, can target their specific needs and produce optimal outcomes. Refugee participation in research is important as exclusion may create systems of care directed at the 'mainstream', limiting the ability of research to reduce inequities in health. (67)

A particular strength in the study design was the utilisation of an existing
collaborative nurse-led model of care to access families and provide ongoing care.
Refugee nurses working within the model of care, known to and trusted by families,
were employed to undertake this research to capitalise on existing relationships with
families, GPs and service networks. The interconnectedness with local resources

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research-funded suite of
recommendations more likely to
ts a tension between optimal
clinical care and different
minimise bias, and research using
tems to maximise recruitment.
tent coercion to participate, which
are highly linked. (64-68) On the
care that the research identifies
ages. (69)
itudinal studies and occurs for
nts or loss of interest. (58,70) We
population due to cultural and
xperience, such as mistrust of
ing immigration status. In contrast,
gaged at Year 2 and the majority
r local studies in vulnerable
% at 3 years (33). Retention an
others was 77.4% at 3 years; the
ntaged urban community retained
on in this study reflects the
retain the sample with specific
le timing of visits and willingness of
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371	and infrastructure, rather than a separate vertical research-funded suite of
372	interventions, makes the implementation of future recommendations more likely to
373	be sustainable. However this study design presents a tension between optimal
374	research, with research staff at arm's-length from clinical care and different
375	researchers completing follow-up assessments to minimise bias, and research using
376	known clinicians embedded in existing service systems to maximise recruitment.
377	Ethical research should ensure there is no inadvertent coercion to participate, which
378	may be more difficult if clinical care and research are highly linked. (64-68) On the
379	other hand, participants are more likely to access care that the research identifies
380	they require if there are close research-clinical linkages. (69)
381	Attrition is more common in the early years of longitudinal studies and occurs for
382	various reasons including relocation, time constraints or loss of interest. (58,70) We
383	expected amplification of this effect in the refugee population due to cultural and
384	language barriers, or precipitated by the refugee experience, such as mistrust of
385	researchers and concerns about the results affecting immigration status. In contrast,
386	once participants were recruited, 100% remain engaged at Year 2 and the majority
387	(85%) at Year 3; retention was higher than in other local studies in vulnerable
388	populations. The refugee youth study retained 78% at 3 years (33). Retention an
389	urban birth cohort of Aboriginal babies and their mothers was 77.4% at 3 years; the
390	MESCH sustained home visiting trial in a disadvantaged urban community retained
391	only 62.5% at 30 months. (70-72) The high retention in this study reflects the
392	considerable effort made by the research team to retain the sample with specific
393	retention strategies, particularly home visits, flexible timing of visits and willingness of
394	the research team to assist families with any challenges confronting them, including
395	housing and education.

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396	Measurement instrument selection is important and unfortunately developmental and
397	social-emotional wellbeing screening tools have not been validated in refugee
398	children. (48) Children's responses to a developmental assessment are likely to
399	reflect their experience as well as their cognitive ability, which impacts on their
400	scoring in relation to language, interpretation of unfamiliar images used in the testing
401	kit and exposure to play, literacy and numeracy materials (such as writing name and
402	address, threading beads, knowing colours, using scissors, swinging on a swing).
403	Cultural and family practices also influence the usefulness of standardised tests
404	especially in the personal-social domain of independent self-help skills and teaching
405	skills such as waving "bye-bye". (73-75) Methodologies are proposed for adapting
406	test materials and procedures to make tools 'culturally appropriate' but it is almost
407	impossible to develop 'culture-free' cognitive tools and there is value in having a
408	generally applicable expectations and standards for children's development. (76)
409	Furthermore tool adaptation to address cultural variation requires significant
410	expertise, such as the typical progression of language in native speakers, and this
411	would limit usefulness of the instrument.
412	Any assessment is vulnerable to intrinsic error as a result of people wanting to

Any assessment is vulnerable to intrinsic error as a result of people wanting to please the researcher. This may be amplified in the refugee setting as parents may associate the child's performance as a reflection of their family and community, fear impact of the child's results on their immigration status, and fear interventions that may remove children from their care. This was the explicit reason for conducting developmental assessments using researcher observed, play-based rather than parent reported skills.

An additional issue is that social-emotional wellbeing measurement, assessed using
the parent completed SDQ, is likely to underestimate a child's level of social-

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1 2		
2 3 4	421	emotional distress in this context and does not specifically assess aspects unique to
5 6	422	the refugee experience such as relocation, food insecurity, trauma exposure and
7 8	423	safety. (58) These issues could be considered for an adapted version of the SDQ for
9 10 11	424	refugee children, but at the risk of creating a different 'norm'.
12 13	425	A fundamental challenge in conducting this study was that professional health care
14 15	426	interpreters were expensive and availability was limited due to face to face
16 17 18	427	interpreters not being available for some language groups (e.g. Amharic) and
19 20	428	interpreter services prioritising clinical consultations over research requests. Yet
21 22	429	interpreters were considered essential for families to give informed consent and for
23 24	430	ongoing participation. The need for interpreters also increased the length of
25 26	431	assessment time, affecting maintaining the child's attention, but prior interpreter
27 28 29	432	training was rarely possible because of availability constraints. Furthermore some
30 31	433	emerging local refugee communities were so small that there were concerns
32 33 34	434	regarding interpreter confidentiality.
35 36	435	This research can be described as 'action research' where the engaged partners
37 38	436	include researchers, service delivery agencies and government policy and
39 40 41	437	implementation sectors, and the researchers are striving to improve health and
42 43	438	service delivery for participants. (77,78) Whilst this may impact on the "purity" of an
44 45	439	observational longitudinal study, it allows for ethical research in communities in
46 47	440	whom researchers would otherwise be passively observing and documenting unmet
48 49	441	health needs. An interesting consequence of such research, particularly since it is
50 51	442	based in one region, may be that awareness of child development and social-
52 53 54	443	emotional health is highlighted to service delivery staff and may change their practice
55 56	444	in the longer term. Clinician-researchers can thus serve as effective "bridges"
57 58 59	445	between the research and practice communities and can facilitate both the
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development of clinically relevant research and the dissemination of evidence-based
treatments into routine clinical services. (68, 69)

449 Future plans

Consideration of many important factors in conducting ethical research in this highly vulnerable population resulted in retention of the sample with few families lost to follow-up once enrolled. This study was limited by small sample size, but we offset this by investing in effective retention strategies to minimise attrition. This longitudinal cohort study is the first of its kind in a refugee child population and demonstrates that it was feasible and that the measures employed were acceptable to families. The establishment of this cohort provides the opportunity for the research team to gather valuable data about the early settlement experience, risk and protective factors and long term health and wellbeing outcomes in refugee children. The next phase of the research is to describe and analyse this data. The overall aim will to identify refugee children in need of additional surveillance and intervention to optimise their health and wellbeing outcomes, and to inform service delivery into the future.

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5 6 7	470	Karen Zwi conceived of the study, and provided leadership in its design and
8 9	471	coordination, conceptualised the analysis and drafted the manuscript. Santuri
10 11	472	Rungan performed statistical analysis and drafted the manuscript. Sue Woolfenden
12 13 14	473	participated in the study design and reviewed the manuscript. Katrina Williams
15 16	474	participated in the study design and reviewed the manuscript. Lisa Woodland
17 18	475	participated in study design and coordination, performed statistical analysis and
19 20	476	reviewed the manuscript. All authors read and approved the final manuscript.
21 22 23	477	
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27 28 29	479	The authors declare that they have no competing interests.
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484	Text Box 1
485	The structured interview information includes:
486	• need for and access to health services over the previous three months, including
487	health problems/injuries experienced by the child; visits to the GP and other
488	health professionals; presentations to Emergency Department (ED) or hospital;
489	immunisation or preventive health activities;
490	access to socio-economic resources (such as salaries, grants and pensions);
491	• access to community support (such as neighbours, religious and/or community
492	organisations);
493	• family stressors and life events post arrival (including moving house or death of
494	family members);
495	exposure to perceived racism or other forms of discrimination;
496	• experience of the study questionnaire (whether it was easy to understand,
497	respectful, produced any confusion or uncomfortable feelings)
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1 2		
3 4	501	Text Box 2
5 6 7	502	Retention strategies to minimise attrition include:
8 9 10	503	Conducting a small pilot study to ensure that tools and questionnaires were
11 12	504	acceptable to families;
13 14	505	Ensuring phone-calls and interviews were scheduled at convenient times for
15 16	506	families;
17 18 19	507	Conducting assessments in the participants' homes;
20 21	508	Employing multiple call back strategies to make initial contact and to convert
22 23	509	contact into a completed interview;
24 25 26	510	Conducting interviews which engage and interest respondents;
20 27 28	511	 Providing feedback to parents about the outcomes of screening;
29 30	512	• Undertaking to organise further services as required as well as support to access
31 32	513	appointments;
33 34 35	514	Encouraging community support through regular feedback to local community
36 37	515	organisations and settlement services, participation in community health
38 39	516	promotion activities and written information;
40 41	517	Working closely with GPs and settlement services who could provide updated
42 43 44	518	contact details for families.
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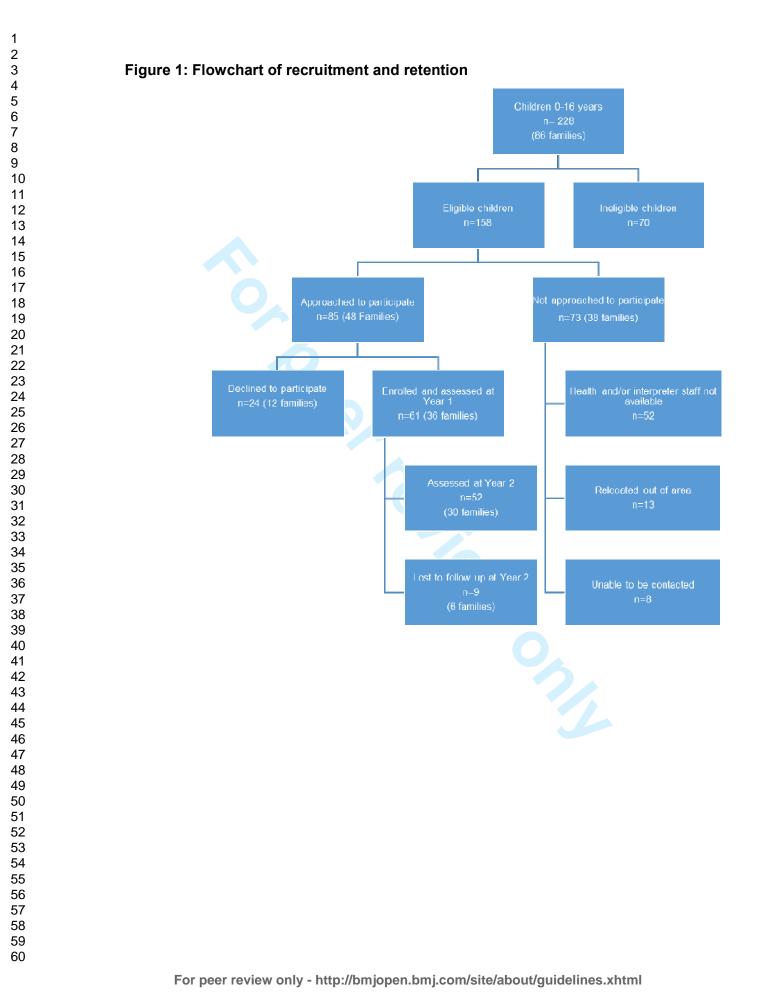
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Outcome	Children aged 6 months to 5 years	Children aged 5 years to 17 years	Timing of assess- ment	Rationale
Physical health	 Full blood count, renal and liver function tests Ferritin level Vitamin D level Serology for hepatitis B, hepatitis C, HIV, syphilis, schistosomiasis, strongyloides and immunity to rubella, measles and mumps. Malaria thin and thick smear, and a rapid antigen test. QuantiFERON TB Gold (QFN) 	 Full blood count, renal and liver function tests Ferritin level Vitamin D level Serology for hepatitis B, hepatitis C, HIV, syphilis, schistosomiasis, strongyloides and immunity to rubella, measles and mumps. Malaria thin and thick smear, and a rapid antigen test. QuantiFERON TB Gold (QFN) Child's height, weight 	On arrival	Child health is associated with health in later life ⁵²
	and body mass index (BMI)	and body mass index (BMI)	arrival Year 2 Year 3	Objectively the objective of the objecti
Develop- ment	Australian Developmental Screening Tool (ADST): Personal/Social Language Cognitive Fine Motor Gross Motor		Year 2 Year 3	Child development associated with school readiness, social development and later academic achievement ^{54,55}
Social- emotional wellbeing		Strengths and Difficulties Questionnaire (SDQ)	Year 2 Year 3	Social- emotional wellbeing associated with positive health

Table 1: Mo C . I. 11 .I . h .

1 2 3		
4		and educational outcomes ^{56,57}
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Table 2: Measurement of risk and protective factors

	Risk and protective factors	Measurement instrument	Timing of Assessment
Child factors	 age gender physical health on arrival presence of chronic disease BMI 	 physical health assessment structured questionnaire 	On arrival Year 2 Year 3
Family factors	 family composition parental disclosure of trauma time in refugee camp region of origin 	 Social Readjustment Ratings Scale (SRRS) structured questionnaire 	Year 2 Year 3
Settlement factors	 stressful life events in last year employment and study status English language proficiency socio-economic resources experience of discrimination access to health care 	 Social Readjustment Ratings Scale (SRRS) structured questionnaire 	Year 2 Year 3

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Table 3: Demographic details of eligible population, study sample and respondent characteristics

Ob any stanistics of O			Eligible Children (n=158)		Study Sampl (n=61
Characteristics of C	hild	Number	Descenteres	Nivershaan	Deveetee
Condor	Mala	Number	Percentage 49%	Number 29	Percentag
Gender	Male Female	78 80	49% 51%	32	48% 52%
Mean age on arrival	remaie	9	51%	4	527
(years)		9		4	
WHO Region	African	66	42%	20	33%
(County of origin)	DR Congo	00	42.70	12	00
(000) 0. 0g)	Ethiopia			2	
	Kenya			2	
	Malawi			2	
	Burundi			1	
	Тодо			1	
	Eastern	41	26%	13	219
	Mediterranean			F	
	Iran			5	
	Iraq Lebanon			5	
	Lebanon			5	
	Europe	1	<1%	0	00
	South East Asia	50	32%	28	469
	Burma			28	
Languages Spoken at Home					
at nome	Amharic			2	3
	Arabic			8	13
	Burmese			13	22
	Chin Senthang			2	3
	English			4	7
	Farsi	4		5	8
	French			2	3
	Karen			10	17
	Karenni			3	5
	Kirundi			3	5
	Swahili			8	13
Characteristics of P					
Gender (n=60)	Male			23	38
	Female			37	62
Prior Education (n=54)	None			4	7
	Primary			15	27
	Secondary			23	43
	University			9	17
	Trade			3	6
Employment in home country (n=53)	Professional			17	32
	Semi-skilled/ unskilled			19	36
	Voluntary			5	9
	Unemployed			12	23
	artner of Primary Res	ondent			
Gender (n=41)	Male			18	44
D L U	Female			23	56
Prior Education	None			1	3
(n=34)	Primary			11	32
	Secondary			16	47

	University Trade	6 0	18% 0%
Employment in home country (n=34)	Professional	11	32%
	Semi-skilled/ unskilled	16	47%
	Voluntary	3	9%
	Unemployed	4	12%

Section/Topic	ltem #	Recommendation	Reported on page #
Title and abstract	1	(<i>a</i>) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction	•		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5-6
Objectives	3	State specific objectives, including any prespecified hypotheses	7
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(<i>a</i>) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	8
		(b) For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	10-12
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	13
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	12-13
Statistical methods	12	(<i>a</i>) Describe all statistical methods, including those used to control for confounding	12-13
		(b) Describe any methods used to examine subgroups and interactions	n/a as this cohort study presents cohort creatior methods, baseline data and future plans
		(c) Explain how missing data were addressed	n/a
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and	13-14
		analysed	

		(b) Give reasons for non-participation at each stage	13
		(c) Consider use of a flow diagram	Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	13-14 Table 1
		(b) Indicate number of participants with missing data for each variable of interest	n/a
		(c) Summarise follow-up time (eg, average and total amount)	14
Outcome data	15*	Report numbers of outcome events or summary measures over time	13-14
Main results	16	(<i>a</i>) Give unadjusted estimates and, if applicable, confounder- adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
		(b) Report category boundaries when continuous variables were categorized	n/a
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	18	Summarise key results with reference to study objectives	12-14
Limitations			17-19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-20 Discussion
Generalisability	21	Discuss the generalisability (external validity) of the study results	15-20 Discussion
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Methods for a longitudinal cohort of refugee children in a regional community in Australia

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Primary Subject Heading :	Paediatrics
Secondary Subject Heading:	Public health
Keywords:	Community child health < PAEDIATRICS, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Public health < INFECTIOUS DISEASES
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2 3	1	Title
4 5 6	2	Methods for a longitudinal cohort of refugee children in a regional community in
7 8	3	Australia
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1		
2 3 4	39	Abstract
5 6	40	Purpose: Few studies explore the long term health and wellbeing of refugee
7 8	41	children. A cohort of refugee children was created to determine health and wellbeing
9 10 11	42	outcomes over time. This article describes the methodology used to conduct a
12 13	43	longitudinal cohort study in refugee children in a regional community, including
14 15	44	sample characteristics and effectiveness of recruitment and retention strategies.
16 17	45	Participants: Newly arrived refugee children settling in a regional part of Australia
18 19 20	46	and aged 6 months to 15 years one month were recruited between 2009 and 2013
20 21 22	47	and 85% followed for 31 months on average.
23 24 25	48	Method and design: General Practitioners conducted health and pathology
26 27	49	examinations shortly after arrival. Additional follow up assessments were conducted
28 29	50	by the research team at an average of 13 months after arrival for the first (Year 2)
30 31	51	and 31 months for the second (Year 3) assessment. Children under 5 years had
32 33 34	52	developmental and children aged 4-17 years had social-emotional screening.
35 36	53	Families were assessed for risk and protective factors using a structured interview
37 38	54	and the Social Readjustment Ratings Scale (SRRS). Participant experience of the
39 40 41	55	research was explored.
42 43	56	Findings to date: Eligibility criteria were met by 158 of 228 (69%) newly arrived
44 45	57	children, 61 of whom (39%) were enrolled. Retention was 100% (n=61) at Year 2
46 47 48	58	and 85% at Year 3. The study sample was younger than and had an over-
49 50	59	representation of African refugees as compared to the eligible population. Parents
51 52 53	60	reported the research was respectful.
54 55	61	Future plans: This study demonstrates that a longitudinal cohort study in a refugee
56 57 58 59	62	child population is feasible and acceptable, and retention rates can be high. The

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63	establishment of this cohort provides the opportunity to analyse valuable data about
64	the early settlement experience, risk and protective factors and long term health and
65	wellbeing outcomes in refugee children.
66	Key Words: Refugee, children, development, cohort, longitudinal, health, wellbeing,
67	Community child health, PAEDIATRICS
68	
69	Strengths and limitations
70	 a strength in the study design was recruitment through an established high
71	uptake population-based screening program for refugees, and utilising trusted
72	nurses to enrol families and provide ongoing care
73	• the study demonstrated feasibility and acceptability in examining a wide range
74	of risk and protective factors and measuring health and wellbeing outcomes
75	over 2-3 years in a population known to be challenging to follow up
76	a key strength was the consideration of many important factors in conducting
77	ethical research in this highly vulnerable population, creating the potential to
78	add to the evidence base, gather valuable data, and contribute to policy and
79	practice change
80	• we sought to offset an important limitation, small sample size, by investing in
81	retention strategies to minimise attrition, which were effective once
82	participants were recruited
83	limited availability of professional health care interpreters was a key challenge
84	in recruitment and the need for interpreters also increased the length of
85	assessment time and study costs

Introduction

wellbeing". (17-19)

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	87	Australia accepts around 13 000 – 20 000 refugees per year under the humanitarian
	88	program, with 40 to 50% of these entrants being children and young people below 25
	89	years. (1) Children from a refugee background often arrive in Australia with unmet
	90	health, developmental and socioemotional needs due to a combination of factors
	91	including forced migration, suboptimal living conditions and limited access to
	92	healthcare. (2,3) Refugee children are particularly at risk of adverse developmental
	93	and mental health outcomes because of the refugee experience itself and the
	94	process of resettlement. (4-6) However, whilst routine health screening on arrival is
	95	recommended by the Royal Australasian College of Physicians (RACP) and detects
	96	many significant and treatable health problems, the need for routine screening of
	97	developmental or social-emotional wellbeing in the period after resettlement has not
	98	been formally examined in cross sectional or prospective studies due to challenges
	99	in conducting such studies in refugee populations. (7-13)
1	100	Prospective studies are advantageous in that they allow researchers to track
1	101	individual children over time, thereby reducing recall bias associated with
1	102	retrospective studies. They can gather information on risk and protective factors
1	103	associated with key outcomes, and thus identify children at higher risk of poor
1	L04	outcomes. (14-16) The Australian National Health and Medical Research Council
1	105	(NHMRC) provides recommendations for research in vulnerable communities,
1	106	including that such research be descriptive in nature, longitudinal in design, collect
1	107	evidence to effect change and be underpinned by an ethical theoretical framework
1	108	that guides design and implementation to produce robust data on health and

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110	Research in refugee children presents multiple challenges, including (1) access to a
111	suitable cohort; (2) language and cultural barriers; (3) lack of cross-cultural validation
112	of standardised screening tools; and (4) working with vulnerable children and
113	families, including parental concerns about research participation. Furthermore, long-
114	term follow up and interpreter costs make such research expensive to undertake in
115	an ethical manner. These challenges have led to systematic exclusion of refugee
116	children from key longitudinal research studies in Australia. (20,21) The Longitudinal
117	Study of Australian Children (LSAC) does not include sufficient refugee children to
118	allow identification of their specific needs and the Longitudinal Survey of Immigrants
119	to Australia (LSIA) focuses on adult immigrants as the primary participants. (20,21)
120	One study of 97 refugee youth settling in Australia achieved follow up for 3 years and
121	identified perceived discrimination as a key determinant of self-rated wellbeing. (16)
122	For this research, a cohort of refugee children was created in a regional community
123	in Australia. This article describes the methodology used to conduct this longitudinal
124	cohort study, and describes sample characteristics, and the effectiveness of
125	recruitment and retention strategies employed. The study was designed to explore
126	how refugee children are tracking over time, particularly in relation to their
127	development and social-emotional wellbeing, and risk and protective factors
128	associated with these outcomes.
129	
130	
131	Methods and design

Sotting

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132	Setting
133	The Illawarra region of New South Wales (NSW), Australia, has a long history of
134	refugee resettlement including European communities following World War II, the
135	Vietnamese community in the 1970s and the Serbian, Croatian and Bosnian
136	communities in the 1990s. The most recent arrivals are from African countries,
137	Burma and the Middle East. (1) In this region, a collaborative nurse-led community
138	based model of care has been in place since 2007. This model operates through
139	settlement services, which link new arrivals with a network of local refugee-friendly
140	general practitioners (GPs), who provide initial health screening and ongoing family-
141	centred care. Refugee Health Nurses (RHNs) provide support to GPs and ensure
142	health needs are addressed. Specialist health services provide training forums,
143	screening and management guidelines, access to rapid tertiary-level consultative
144	expertise, and specialised Refugee Health Clinics. This collaborative model of care
145	has been shown to be successful in undertaking physical health screening of the
146	entire population (100%) of newly arrived refugee children settling in the region.
147	(22,23)

Recruitment and participants

Subjects were recruited into the study through the existing model of care described
and building on the established relationships with refugee communities and health
professionals working with them. Eligible subjects were children aged 0 to 15 years,
who arrived in Australia on permanent humanitarian visas between May 2009 and
April 2013, and settled within the regional catchment area of the Illawarra
Shoalhaven Local Health District. A maximum of two children per family were
eligible. We recruited participants from eligible children who arrived between May

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2009 and April 2013. Soon after arrival, RHNs approached families with information
about the study seeking permission to contact, full written consent and permission to
recruit for research purposes. If obtained, the family was contacted for follow up
assessments. Follow up assessments occurred between April 2010 – January 2014
(Year 2 assessments) and March 2013 – August 2014 (Year 3 assessments).

The RHNs were chosen as the primary research assistants because they were respected and trusted by settlement services and community members. The RHNs also provided a safety net for this vulnerable population because they were skilled in referring children and families to the complex network of settlement and mainstream health services available. All interactions, apart from administrative telephone calls, were conducted with a face to face professional health care interpreter present.

168 (Figure 1)

170 Measurement schedule

The final measurement schedule was as follows: General Practitioners conducted the physical health examinations and pathology testing on all children shortly after arrival (average 20.4 days; range 6 to 98 days), consistent with the model of care (within the first year; Year 1 assessments). Research assessments were carried out by the research team, which included the RHN and paediatric doctors. The first follow up assessment occurred at Year 2 (average 13 months after arrival; range of 6-23 months) and the second follow up assessment at Year 3 (average 31 months) after arrival; range of 21-40 months). Developmental and social-emotional screening assessments were delayed until Years 2 and 3 to allow for a period of adjustment and to reduce capturing immediate resettlement stress.

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181	At Years 2 and 3 children aged 6 months to 5 years old had developmental
182	screening assessments using the Australian Developmental Screening Tool (ADST);
183	children aged 4-17 years had social-emotional screening assessments using the
184	Strengths and Difficulties Questionnaire (SDQ). Children aged 4 - 5 years were
185	eligible for both screening assessments. (24,25) Key outcomes for the study for
186	physical health, child development (ADST) and social-emotional health (SDQ) are
187	outlined in Table 1.
188	

189 Table 1: Measurement of child outcome measures, by age group

Outcome	Children aged 6 months to 5 years*	Children aged 4 years to 17 years*	Timing of assess- ment	Rationale
Physical health	 Full blood count, renal and liver function tests Ferritin level Vitamin D level Serology for hepatitis B, hepatitis C, HIV, syphilis, schistosomiasis, strongyloides and immunity to rubella, measles and mumps. Malaria thin and thick smear, and a rapid antigen test. QuantiFERON TB Gold (QFN) 		On arrival	Child health is associated with health in later life ³⁸
	Child's height, weight and	d body mass index (BMI)	On arrival Year 2 Year 3	Underweight is associated with poor school performance ^{38,} Obesity is associated with several health problems ³⁹
Develop- ment	Australian Developmental Screening Tool (ADST): Personal/Social Language Cognitive Fine Motor Gross Motor	0,20	Year 2 Year 3	Child development associated with school readiness, social development and later academic achievement ⁴⁰
Social- emotional wellbeing		Strengths and Difficulties Questionnaire (SDQ)	Year 2 Year 3	Social- emotional wellbeing associated with positive health and educationa outcomes ^{42,43}

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All families were assessed for risk and protective factors using a structured interview and the Social Readjustment Ratings Scale (SRRS). (26) In keeping with the bio-ecological model of child health risk and protective factors were classified into: (i) child factors (age, gender, physical health on arrival), (ii) family factors (family composition, parental disclosure of trauma, time in refugee camp, region of origin) and (iii) settlement factors (stressful life events in last year, employment and study status, English language proficiency, socio-economic resources, experience of discrimination and access to health care) (Table 2). (27) Children who scored in the abnormal or borderline ranges on the developmental or social-emotional screening assessments were referred to the local Refugee Child Health clinical team or their GP. As part of the structured interview parents were asked about their experience of participating in the research and whether the study questionnaire was easy to understand and respectful or produced any confusion or uncomfortable feelings. Given the importance of maintaining follow up in this cohort, a number of strategies to minimise attrition were employed (Text Box 1).

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I	Retention strategies to minimise attrition include:
•	 conducting a small pilot study to ensure that tools and questionnaires were
	acceptable to families;
•	ensuring phone-calls and interviews were scheduled at convenient times for
	families;
•	 conducting assessments in the participants' homes;
•	• employing multiple call back strategies to make initial contact and to convert
	contact into a completed interview;
•	 conducting interviews which engage and interest respondents;
•	 providing feedback to parents about the outcomes of screening;
•	 undertaking to organise further services as required as well as support to acce
	appointments;
•	encouraging community support through regular feedback to local community
	organisations and settlement services, participation in community health
	promotion activities and written information;
•	• working closely with GPs and settlement services who could provide updated
	contact details for families.

230 Table 2: Measurement of risk and protective factors

	Risk and protective factors	Measurement instrument	Timing of Assessment
Child factors	 age gender physical health on arrival presence of chronic disease BMI 	 physical health assessment structured questionnaire 	On arrival Year 2 Year 3
Family factors	 family composition parental disclosure of trauma time in refugee camp region of origin 	 Social Readjustment Ratings Scale (SRRS) structured questionnaire 	Year 2 Year 3
Settlement factors	 stressful life events in last year employment and study status English language proficiency socio-economic resources experience of discrimination access to health care 	 Social Readjustment Ratings Scale (SRRS) structured questionnaire 	Year 2 Year 3

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232 Measurement instruments

233234 1. Physical Health Assessment

The initial clinical evaluation included a history and examination, screening tests and anthropometric measurements (height, weight and body mass index (BMI)) (Table 1). A schistosomiasis IgG ratio of <0.7 and a strongyloides IgG ratio of <0.8 were considered negative. Malaria screening comprised a thin smear, thick smear and a rapid antigen test. All children had tuberculosis screening using an interferon-y release assay, QuantiFERON TB Gold (QFN). Low ferritin levels (normal: 20-200 micrograms/litre) were used as a marker of iron deficiency. Vitamin D levels were defined as follows: toxicity >250nmol/L; sufficiency 50-230nmol/L; mild deficiency 26-50nmol/L; moderate deficiency 12.5-25nmol/L and severe deficiency <12.5nmol/L. (3) Anthropometric measurements were repeated at Years 2 and 3.

245 2. Development

The Australian Developmental Screening Test (ADST) tool was selected to assess development in younger children because it was a standardised, individually administered, objective and play-based developmental screening test. (24) The tool assessed five domains of development (language, cognitive skills, fine motor skills, personal/social skills and gross motor skills), and could be administered by any trained health worker over approximately 20 minutes. Using published modified diagnostic criteria, specificity and sensitivity of ADST scores correlate well with the gold standard Griffiths Mental Developmental Scales (GMDS). (28) The ADST domains were scored to produce a developmental age in months and categorised into two possible outcomes: (1) normal and (2) monitor (for children requiring review over time but not necessarily intervention).

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3. Social-emotional wellbeing

The parent report version of the Strengths and Difficulties Questionnaire (SDQ) was 58 used to identify social-emotional problems in children and young people from 4 - 17 59 years of age. This tool was selected because it has been validated for use across 60 cultures, was simple and quick to administer and has demonstrated reasonable 61 62 cross informant correlations, good internal consistency and correlation with Rutter scales and the Achenbach Child Behaviour checklist. (29-33) Translated SDQs were 63 used if available (Arabic and Farsi), and the primary respondent was literate in their 64 first language. Interpreters were briefed before assessments to ensure consistency 65 between interpreters and translated SDQs. 66 The SDQ includes 25 items with 5 symptom scales to evaluate emotional symptoms, 67 conduct problems, hyperactivity and inattention, peer relations and prosocial 68 69 behaviour. (25) Scores were generated for each subscale and the Total Difficulties

270 (TD). High SDQ scores indicate increased risk of social-emotional problems. The

271 SDQ scores were classified into 3 categories: (1) normal, (2) borderline and (3)

272 abnormal.

273 **4. Risk and protective factors**

Risk and protective factors were assessed using a structured interview (Text Box 2)

275 and the Holmes and Rahe Social Readjustment Rating Scale (SRRS). (24) The

276 SRRS was used as a measure of the impact of stressful life events such as changes

- in family composition, employment and stability of residence. Scores that were
- greater than 300 on the scale indicated a high risk (over 80% chance) of developing
- a significant illness. (34,35) Risk and protective factors were classified into child,
- family and settlement factors as described above. (27)

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281	Text Box 2
282	The structured interview information includes:
283	need for and access to health services over the previous three months, including
284	health problems/injuries experienced by the child; visits to the GP and other
285	health professionals; presentations to Emergency Department (ED) or hospital;
286	immunisation or preventive health activities;
287	access to socio-economic resources (such as salaries, grants and pensions);
288	access to community support (such as neighbours, religious and/or community
289	organisations);
290	• family stressors and life events post arrival (including moving house or death of
291	family members);
292	exposure to perceived racism or other forms of discrimination;
293	• experience of the study questionnaire (whether it was easy to understand,
294	respectful, or produced any confusion or uncomfortable feelings)
295	
296	
297	Before finalising the measurement schedule, we conducted a small pilot study in 3
298	families to ensure that tools and questionnaires were practical. Based on these
299	assessments and participant feedback, a few questions were altered, repetitive
300	questions were removed and the study measurement instruments were reduced in
301	number to limit questionnaire completion and assessment at each time point to 8
302	hours, conducted over two sessions for each child. We also developed a recruitment
303	strategy of preferentially recruiting the youngest two children in each family.

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Including more children created a heavy respondent burden for the family, the
youngest children were more likely to be at home during school or working hours and
we were particularly interested in capturing as many young children as possible to
assess child development.

308

309 Data management

An Access database was developed to capture the data for the study, including demographic, physical health, child development (ADST) and social-emotional health (SDQ) data and risk and protective factors (SRRS and structured interviews). Information was entered by RHNs.

314 Data Analysis

All data were analysed using SPSS version 22.0 using a predetermined analysis plan. (36) Categorical data were described with frequency percentages. Continuous data were described with means and standard deviations (SD) and effect sizes between groups calculated as the mean difference divided by the pooled SD. (37) The data from the structured interviews of parents' research experience was recorded categorically in Access, coded in SPSS and analysed using quantitative methods.

322 Ethics

Ethics approval was provided by the Human Research Ethics Committee Northern Hospitals Network, South Eastern Sydney Illawarra Area Health Service (HREC Ref No 09/163). Informed consent to participate in the study was sought from parents with a professional health care interpreter present. BMJ Open: first published as 10.1136/bmjopen-2016-011387 on 24 August 2016. Downloaded from http://bmjopen.bmj.com/ on April 16, 2024 by guest. Protected by copyright

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327 Findings to date

Recruitment and retention

In the 4-year period between May 2009 and April 2013, 86 refugee families arrived in the study region with a total number of 228 children aged 6 months to 15 years of age (Figure 1). The eligibility criteria for the study were met by 158 children; the main reason for ineligibility was that two children per family had been enrolled. Of the 158 eligible, 85 (54%) children were approached and 61 children were recruited for the study (27% of all newly arrived children aged 15 years and 39% of all eligible children). The remaining 73 children were not approached for recruitment due to limited availability of interpreters for research purposes and part time research staff (n=52; 71%), families relocating out of the area (n=13; 18%) and inability to contact families (n=8; 11%).

The enrolled sample was similar to the eligible population in terms of gender but the mean age (6 years; SD = 4 years) was younger than the eligible population (9 years; SD = 4.5 years) (Table 3). This is consistent with the recruitment strategy of preferentially including the youngest two children in each family. The sample had similar proportions to the eligible population for the Eastern Mediterranean WHO region of origin (21% versus 26% respectively) but the South East Asian region was over-represented (43% versus 32%) and the African region under-represented (33% versus 42%). This reflected the availability of language specific interpreters available to facilitate recruitment during the study period.

349 Table 3: Demographic details of eligible population, study sample and

350 respondent characteristics

			Eligible Children (n=158)		Study Sample (n=61)
Characteristics of C	hild		-		
-		Number	Percentage	Number	Percentage
Gender	Male	78	49%	29	48%
	Female	80	51%	32	52%
Mean age on arrival		9		4	
(years)			100/		
WHO Region	African	66	42%	20	33%
(County of origin)	DR Congo			12	
	Ethiopia Kenya			2	
	Malawi			2	
	Burundi			1	
	Togo			1	
	logo			•	
	Eastern	41	26%	13	21%
	Mediterranean		_0,0		
	Iran			5	
	Iraq			5	
	Lebanon			3	
	Europe	1	<1%	0	0%
	South East Asia	50	32%	28	46%
	Burma			28	
Languages Spoken					
at Home					
	Amharic			2	3%
	Arabic			8	13%
	Burmese			13	22%
	Chin Senthang			2	3%
	English			4	7%
	Farsi			5	8%
	French			2	3%
	Karen Karenni			10 3	<u>17%</u> 5%
	Kirundi			3	<u> </u>
	Swahili			8	13%
Characteristics of P				0	1370
Gender (n=60)	Male			23	38%
	Female			37	62%
Prior Education	None			4	7%
(n=54)					
	Primary			15	27%
	Secondary			23	43%
	University			9	17%
	Trade			3	6%
Employment in	Professional			17	32%
home country					
(n=53)					
	Semi-skilled/ unskilled	d		19	36%
	Voluntary			5	9%
.	Unemployed	- .		12	23%
	artner of Primary Res	pondent			
Gender (n=41)	Male			18	44%
Discolation di	Female			23	56%
Prior Education	None			1	3%
(n=34)	Drimon				200/
	Primary			11	32%
	Secondary			16	47%

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	University Trade	6	18% 0%
Employment in home country (n=34)	Professional	11	32%
	Semi-skilled/ unskilled	16	47%
	Voluntary	3	9%
	Unemployed	4	12%

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353	Primary respondents of the structured interviews were predominantly mothers (n=32;
354	62%) (Table 3). All children (100%) were assessed at Year 2 (n=61) between April
355	2010 – January 2014. At Year 3, between March 2013 – August 2014, 52 children
356	from 30 families were assessed, which represented a retention rate of 85%. Five of
357	these children could not have their Year 3 assessment within the study time frame.
358	The children who were lost to follow up were similar to the study sample in terms of
359	gender, age, WHO region of origin, language spoken at home, prior education and
360	employment of the primary respondent.
361	
362	Participant experience:

363 The study was generally considered acceptable to parents. The majority found the questionnaires easy to answer (Year 2: 33/39, 85%; Year 3: 35/42, 83%) without 364 being confusing (Year 2: 28/39, 72%; Year 3: 43/47, 91%) or raising uncomfortable 365 feelings (Year 2: 37/37, 100%; Year 3: 36/39, 92%), and all parents found the 366 367 research respectful.

368

369 Management of the project

- The Research Implementation Committee managed the day-to-day operational 370 371
 - aspects of the study and met monthly. A Project Management Committee with

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372	representatives from each of the partner organisations as well as policy and
373	implementation agencies met quarterly for strategic oversight, reporting and
374	feedback.
375	
376	Discussion
377	A growing body of research demonstrates that optimising development (including
378	language and cognitive development, social-emotional and physical health) in early
379	childhood has positive long term benefits including increasing children's IQ, school
380	achievement, employment, mental health and socio-economic status in adulthood.
381	(38-43) Children from a refugee background are often exposed to significant levels of
382	trauma and instability during the early years which increases their risk of poor
383	developmental and social-emotional health outcomes. (44-49) This longitudinal
384	cohort study was designed to utilise an existing high uptake model of care to access
385	the newly arrived refugee population to measure health, developmental and socio-
386	emotional wellbeing outcomes and examine a wide range of risk and protective
387	factors.
388	Research in refugee populations may present specific challenges but studies such
389	as this can ensure that services are evidence based, target refugee-specific needs
390	and produce optimal outcomes. Refugee participation in research is important as
391	exclusion may create systems of care directed at the 'mainstream', limiting the ability
392	of research to reduce inequities in health. (50,51)
393	This prospective cohort study provides the methodology to achieve this end but has
394	presented a number of logistic difficulties. Recruitment was anticipated to be a
395	challenge in establishing this cohort and was indeed low at 39% of eligible children.

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396	However participant refusal, which was expected, occurred in only 15% of those
397	approached. A fundamental challenge in conducting this study was that professional
398	health care interpreters were expensive and availability was limited, especially for
399	some new and emerging language groups (e.g. Amharic). Understandably
400	interpreter services prioritised clinical consultations over research requests.
401	This study was limited by small sample size, but we offset this by investing in
402	effective retention strategies to minimise attrition. Attrition is more common in the
403	early years of longitudinal studies and occurs for various reasons including
404	relocation, time constraints or loss of interest. (5744,52) We expected amplification
405	of this effect in the refugee population due to cultural and language barriers, or
406	precipitated by the refugee experience, such as mistrust of researchers and
407	concerns about the results affecting immigration status. In contrast, once participants
408	were recruited, 100% remained engaged at Year 2 and the majority (85%) at Year 3.
409	Retention was higher than in other local studies in vulnerable populations in which
410	retention at $2\frac{1}{2}$ to 3 years ranged from 62.5% in an home visiting trial in a
411	disadvantaged urban community to 78% in both a refugee youth study and an urban
412	birth cohort of Aboriginal babies and their mothers. (16; 52-54) The high retention in
413	this study reflects the considerable effort made by the research team to retain the
414	sample with specific retention strategies, particularly home visits, flexible timing of
415	visits and willingness of the research team to assist families with any challenges
416	confronting them, including housing and education.
117	Measurement instrument selection is important and unfortunately developmental and

417 Measurement instrument selection is important and unfortunately developmental and
418 social-emotional wellbeing screening tools have not been validated in refugee
419 children. Children's responses to the developmental tool used in this study are likely
420 to reflect their experience as well as their cognitive ability, and may reduce their

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421	scores in relation to language and interpretation of unfamiliar images used in the
422	testing kit and exposure to play, literacy and numeracy materials (such as writing
423	name and address, threading beads, knowing colours, using scissors). Cultural and
424	family practices also influence the usefulness of standardised tests but it is almost
425	impossible to develop 'culture-free' cognitive tools and there is value in having
426	generally applicable expectations and standards for children's development. (55-58)
427	Any assessment is vulnerable to intrinsic error such as wanting to please the
428	researcher. This may be amplified in the refugee setting as parents may view the
429	child's performance as a reflection of their family and community and fear impact of
430	the child's results on their immigration status. This was the explicit reason for
431	conducting developmental screening assessments using researcher observed, play-
432	based rather than parent reported skills.
433	A fundamental challenge in conducting this study was that professional health care
434	interpreters were expensive and availability was limited due to face to face
435	interpreters not being available for some language groups and interpreter services
436	prioritising clinical consultations over research requests. Yet interpreters were
437	considered essential for families to give informed consent and for ongoing
438	participation. The need for interpreters also increased the length of assessment time,
439	affecting maintaining the child's attention. Furthermore some emerging local refugee
440	communities were so small that there were concerns regarding interpreter
440 441	communities were so small that there were concerns regarding interpreter confidentiality.
441	confidentiality.

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445	service delivery for participants using an existing collaborative model of care to
446	access families and provide ongoing care. (59,60) Refugee nurses working within
447	the model of care, known to and trusted by families, were employed to undertake this
448	research to capitalise on existing relationships with families, GPs and service
449	networks. The interconnectedness with local resources and infrastructure, rather
450	than a separate vertical research-funded suite of interventions, makes the
451	implementation of future recommendations more likely to be sustainable. However
452	this study design presents a tension between optimal research, with research staff at
453	arm's-length from clinical care and different researchers completing follow-up
454	assessments to minimise bias, and research using known clinicians embedded in
455	existing service systems to maximise recruitment. Whilst this may impact on the
456	"purity" of an observational longitudinal study, it allows for ethical research in
457	communities in whom researchers would otherwise be passively observing and
458	documenting unmet health needs. Participants are more likely to access care that
459	the research identifies they require if there are close research-clinical linkages. (61)
460	However, rethical research should ensure there is no inadvertent coercion to
461	participate, which may be more difficult if clinical care and research are highly linked.
462	(17-19,51,62)
463	An interesting consequence of such research, particularly since it is based in one
464	region, may be that increased exposure to child development and social-emotional

health may change the clinical practice of service delivery staff. Clinician-researchers

can thus serve as effective "bridges" between the research and practice communities

and can facilitate both the development of clinically relevant research and the

dissemination of evidence-based practice into routine clinical services. (61,62)

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470 Future plans

This longitudinal cohort study is the first of its kind in a refugee child population and demonstrates feasibility and acceptability of the measures employed to families. The establishment of this cohort provides the opportunity for the research team to gather valuable data about the early settlement experience, risk and protective factors and long term health, development and socioemotional wellbeing outcomes in refugee children.

The next phase of the research is to describe the physical health, development and social-emotional wellbeing of the enrolled children over time. Risk and protective factors will be described and classified into child, family and settlement factors. The key aim of this next stage is to identify risk and protective factors for health outcomes so that children at risk can be identified early after arrival and be prioritised for additional surveillance and intervention. The overall objective is to optimise the health and wellbeing outcomes of refugee children, and to inform service delivery to refugee families into the future. To this end key service providers and policy makers have been involved in all phases of this study. Furthermore funding is being sought to continue follow up with the existing cohort of refugee children and to increase the sample size by including other jurisdictions.

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1 2 3 4	494	Authors' Contributions
5 6 7	495	Karen Zwi conceived of the study, and provided leadership in its design and
8 9	496	coordination, conceptualised the analysis and drafted the manuscript. Santuri
10 11	497	Rungan performed statistical analysis and drafted the manuscript. Susan
12 13	498	Woolfenden participated in the study design and reviewed the manuscript. Katrina
14 15 16	499	Williams participated in the study design and reviewed the manuscript. Lisa
17 18	500	Woodland participated in study design and coordination, performed statistical
19 20	501	analysis and reviewed the manuscript. All authors read and approved the final
21 22	502	manuscript.
23 24	503	
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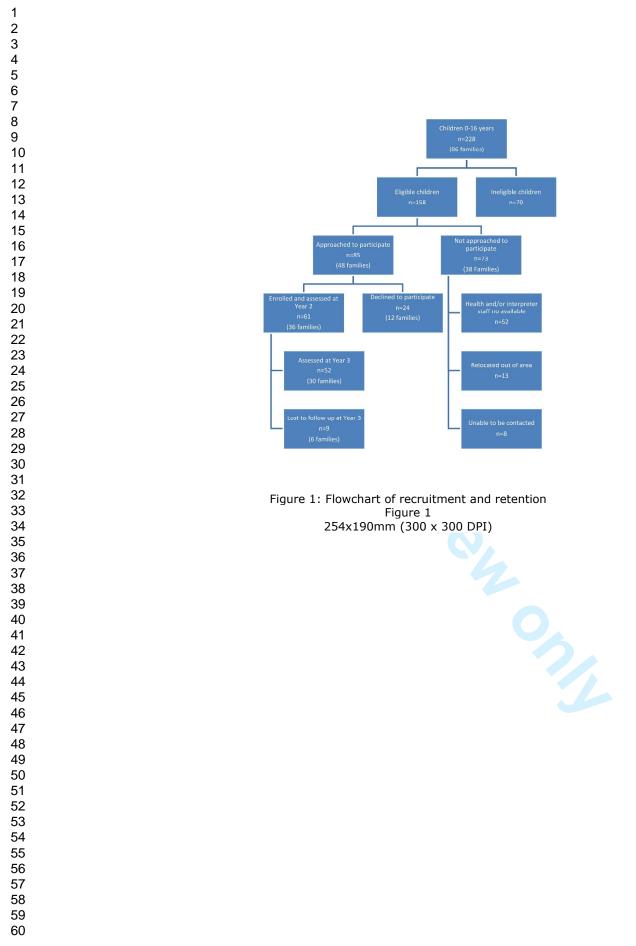
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Section/Topic	ltem #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in	1
		the title or the abstract	
		(b) Provide in the abstract an informative and balanced	3
		summary of what was done and what was found	
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the	5-6
		investigation being reported	
Objectives	3	State specific objectives, including any prespecified hypotheses	<u>6</u> 7
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including	7
Jetting	5	periods of recruitment, exposure, follow-up, and data	,
		collection	
Participants	6	(a) Give the eligibility criteria, and the sources and methods of	<u>7-</u> 8
T articipants	Ū	selection of participants. Describe methods of follow-up	<u>/</u> 0
		(b) For matched studies, give matching criteria and number of	n/a
		exposed and unexposed	170
Variables	7	Clearly define all outcomes, exposures, predictors, potential	9 <u>; Table 1 and Table 2</u>
Variables	,	confounders, and effect modifiers. Give diagnostic criteria, if	
		applicable	
Data sources/	8*	For each variable of interest, give sources of data and details	10-12
measurement	-	of methods of assessment (measurement). Describe	
		comparability of assessment methods if there is more than one	
		group	
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	13 <u>; Figure 1</u>
Quantitative	11	Explain how quantitative variables were handled in the	12-13
variables		analyses. If applicable, describe which groupings were chosen	
		and why	
Statistical methods	12	(a) Describe all statistical methods, including those used to	12-13
		control for confounding	
		(b) Describe any methods used to examine subgroups and	n/a as this cohort study
		interactions	presents cohort creation
			methods, baseline data
			and future plans
		(c) Explain how missing data were addressed	n/a
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg	13-14 <u>; Figure 1</u>
		numbers potentially eligible, examined for eligibility, confirmed	
		eligible, included in the study, completing follow-up, and	
		analysed	

Research Checklist STROBE 2007 (v4) Statement for cohort studies

			1
		(b) Give reasons for non-participation at each stage	13
		(c) Consider use of a flow diagram	Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	1 <u>2</u> 3-14 -Table 1<u>;</u> Table 3
		(b) Indicate number of participants with missing data for each variable of interest	n/a<u>13</u>
		(c) Summarise follow-up time (eg, average and total amount)	14 <u>3</u>
Outcome data	15*	Report numbers of outcome events or summary measures over time	13-14 <u>; Table 1 and Table 2</u>
Main results	16	(<i>a</i>) Give unadjusted estimates and, if applicable, confounder- adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
		(b) Report category boundaries when continuous variables were categorized	n/a
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a Table 3
Discussion			
Key results	18	Summarise key results with reference to study objectives	1 2 4-14 <u>8</u>
Limitations			<u>15-</u> 17 _19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-20<u>15-19</u> Discussion
Generalisability	21	Discuss the generalisability (external validity) of the study results	15-20<u>15-16</u> Discussion
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	<u>1921</u>

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Methods for a longitudinal cohort of refugee children in a regional community in Australia

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	·



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1 2 3	38	Abstract	
4 5 6	39	Purpose: Few studies explore the long term health and wellbeing of refugee	
6 7 8	40	children. A longitudinal cohort of refugee children was created to determine health	
9 10	41	and wellbeing outcomes over time. This article describes the methodology used to	
11 12 13	42	conduct this study, including sample characteristics and effectiveness of recruitmer	nt
14 15	43	and retention strategies.	
16 17	44	Participants: Newly arrived refugee children settling in a regional part of Australia	
18 19	45	aged 6 months to 15 years were recruited between 2009 and 2013 and 85%	
20 21 22	46	followed for 31 months on average.	
23 24	47	Method and design: General Practitioners conducted health and pathology	
25 26 27	48	examinations shortly after arrival. Additional follow up assessments were conducte	d
28 29	49	by the research team at an average of 13 months after arrival for the first (Year 2)	
30 31	50	and 31 months for the second (Year 3) assessment. Children under 5 years had	
32 33 34	51	developmental and children aged 4-17 years had social-emotional screening.	
35 36	52	Families were assessed for risk and protective factors using a structured interview	
37 38	53	and the Social Readjustment Ratings Scale (SRRS). Parent experience of the	
39 40	54	research was explored.	
41 42 43	55	Findings to date: Eligibility criteria were met by 158 of 228 (69%) newly arrived	
44 45	56	children, 61 of whom (39%) were enrolled. Retention was 100% (n=61) at Year 2	
46 47	57	and 85% at Year 3. The study sample was younger than and had an over-	
48 49 50	58	representation of African refugees as compared to the eligible population. Parents	
51 52	59	reported that the research was respectful.	
53 54 55	60	Future plans: This study demonstrates that a longitudinal cohort study in refugee	
56 57 58 59 60	61	children is feasible and acceptable, and retention rates can be high. The	3

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62 establishment of this cohort provides the opportunity to analyse valuable data about 63 the early settlement experience, risk and protective factors and long term health and wellbeing outcomes in refugee children. These are necessary to identify refugee 64 children in need of additional support and to guide future service delivery. 65 66 Key Words: Refugee, children, development, cohort, longitudinal, health, wellbeing, 67 Community child health, PAEDIATRICS 68 69 Strengths and limitations 70 a strength in the study design was recruitment through an established high 71 72 uptake population-based screening program for refugees, and utilising trusted 73 nurses to enrol families and provide ongoing care 74 the study demonstrated feasibility and acceptability in examining a wide range 75 of risk and protective factors and measuring health and wellbeing outcomes 76 over 2-3 years in a population known to be challenging to follow up 77 a key strength was the consideration of many important factors in conducting 78 ethical research in this highly vulnerable population, creating the potential to 79 add to the evidence base, gather valuable data, and contribute to policy and practice change 80 81 we sought to offset an important limitation, small sample size, by investing in retention strategies to minimise attrition, which were effective once 82 83 participants were recruited 84 limited availability of professional health care interpreters was a key challenge in recruitment and the need for interpreters also increased the length of 85 assessment time and study costs 86

Introduction

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88	Australia accepts around 13 000 – 20 000 refugees per year under the humanitarian
89	program, with 40 to 50% of these entrants being children and young people below 25
90	years.[1] Children from a refugee background often arrive in Australia with unmet
91	health, developmental and social-emotional needs due to a combination of factors
92	including forced migration, suboptimal living conditions and limited access to
93	healthcare.[2, 3] Refugee children are particularly at risk of adverse developmental
94	and mental health outcomes because of the refugee experience itself and the
95	process of resettlement.[4-6] Routine health screening on arrival is recommended by
96	the Royal Australasian College of Physicians (RACP) and detects many significant
97	and treatable health problems. However the need for routine screening of
98	developmental or social-emotional wellbeing in the period after resettlement has not
99	been formally examined in cross sectional or prospective studies due to challenges
100	in conducting such studies in refugee populations.[7-13]
101	Prospective studies are advantageous in that they allow researchers to track
102	individual children over time, thereby reducing recall bias associated with
103	retrospective studies. They can gather information on risk and protective factors
104	associated with key outcomes, and thus identify children at higher risk of poor
105	outcomes.[14-16] The Australian National Health and Medical Research Council
106	(NHMRC) provides recommendations for research in vulnerable communities,
107	including that such research is descriptive in nature, longitudinal in design, collects
108	evidence to effect change and is underpinned by an ethical theoretical framework
109	that guides design and implementation to produce robust data on health and
110	wellbeing.[17-19]

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111	Research in refugee children presents multiple challenges, including (1) access to a
112	suitable cohort; (2) language and cultural barriers; (3) lack of cross-cultural validation
113	of standardised screening tools; and (4) working with vulnerable children and
114	families, including parental concerns about research participation. Furthermore, long-
115	term follow up and interpreter costs make such research expensive to undertake in
116	an ethical manner. These challenges have led to systematic exclusion of refugee
117	children from key longitudinal research studies in Australia.[20, 21] The Longitudinal
118	Study of Australian Children (LSAC) does not include sufficient numbers of refugee
119	children to allow identification of their specific needs and the Longitudinal Survey of
120	Immigrants to Australia (LSIA) focuses on adult immigrants as the primary
121	participants.[20, 21] Only one longitudinal study of refugee youth has been
122	conducted in Australia and the outcome was limited to self-rated wellbeing.[16]
123	This article describes the methodology used to conduct a longitudinal cohort study of
124	refugee children in a regional community in Australia, including sample
125	characteristics, and the effectiveness of recruitment and retention strategies
126	employed. The purpose of this cohort was to explore how refugee children are
127	tracking over time, particularly in relation to their development and social-emotional
128	wellbeing, and risk and protective factors associated with these outcomes.
129	Methods and design
130	Setting
131	The Illawarra region of New South Wales (NSW), Australia, has a long history of
132	refugee resettlement including European communities following World War II, the
132 133	refugee resettlement including European communities following World War II, the Vietnamese community in the 1970s and the Serbian, Croatian and Bosnian

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Burma and the Middle East.[1] In this region, a collaborative GP-led community based model of care has been in place since 2007. This model operates through settlement services, which link new arrivals with a network of local refugee-friendly general practitioners (GPs), who provide initial health screening and ongoing family-centred care. Refugee Health Nurses (RHNs) provide support to GPs and ensure health needs are addressed. Specialist health services provide training forums, screening and management guidelines, access to rapid tertiary-level consultative expertise, and specialised Refugee Health Clinics. This collaborative model of care has been shown to be successful in undertaking physical health screening of the entire population (100%) of newly arrived refugee children settling in the region.[22, 23]

Recruitment and participants

Subjects were recruited into the study through the existing model of care described and building on the established relationships with refugee communities and health professionals working with them. We recruited participants from eligible children who were aged 0 to 15 years, arrived in Australia on permanent humanitarian visas between May 2009 and April 2013, and settled within the regional catchment area of the Illawarra Shoalhaven Local Health District. A maximum of two children per family were eligible to reduce the respondent burden for the family. We preferentially recruited the youngest two children as they were more likely to be at home during school or working hours and we were particularly interested in capturing as many young children as possible to assess child development.

Soon after arrival, RHNs approached families with information about the study
 seeking permission to contact over time, full written consent and permission to

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160	recruit for research purposes. If obtained, the family was contacted for follow up
161	assessments which occurred between April 2010 – January 2014 (Year 2
162	assessments) and March 2013 – August 2014 (Year 3 assessments).
163	
164	The RHNs were chosen as the primary research assistants because they were
165	respected and trusted by settlement services and community members. The RHNs
166	also provided a safety net for this vulnerable population because they were skilled in
167	referring children and families to the complex network of settlement and mainstream
168	health services available. All interactions, apart from administrative telephone calls,
169	were conducted with a face to face professional health care interpreter present.
170	(Figure 1)
171	
172	Given the importance of maintaining follow up in this cohort, a number of strategies
173	to minimise attrition were employed (Text Box 1).
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1		
2 3 4	178	Measurement instruments
5 6	179	Key outcomes for the study were physical health, child development and social-
7 8	180	emotional wellbeing (Table 1).
9 10	181	
11 12	182	1. Physical Health Assessment
13 14 15	183	The initial clinical evaluation included a history and examination, screening tests and
16 17	184	anthropometric measurements (height, weight and body mass index (BMI)). A
18 19 20	185	schistosomiasis IgG ratio of <0.7 and a strongyloides IgG ratio of <0.8 were
20 21 22	186	considered negative. Malaria screening comprised a thin smear, thick smear and a
23 24	187	rapid diagnostic test. All children had tuberculosis screening using an interferon- γ
25 26	188	release assay, QuantiFERON TB Gold (QFN). Low ferritin levels
27 28	189	(<20micrograms/litre) were used as a marker of iron deficiency. Vitamin D levels
29 30 31	190	were defined as sufficient (50-230nmol/L), mild (26-50nmol/L), moderate (12.5-
32 33	191	25nmol/L) and severe (<12.5nmol/L) deficiency. [8] Anthropometric measurements
34 35	192	were repeated at Years 2 and 3.
36 37 38 39	193	were repeated at Years 2 and 3.2. Development
40 41	194	The Australian Developmental Screening Test (ADST) was selected to assess
42 43	195	development in younger children because of its properties as a standardised,
44 45	196	individually administered, objective and play-based developmental screening test.
46 47 48	197	[24] The tool assesses five domains of development (language, cognitive skills, fine
49 50	198	motor skills, personal/social skills and gross motor skills), and was administered by
51 52	199	the RHN playing with the child and requesting information from the parent over
53 54	200	approximately 30 minutes. Using published modified diagnostic criteria, specificity
55 56 57 58	201	and sensitivity of ADST scores correlate well with the gold standard Griffiths Mental

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Developmental Scales (GMDS).[24] The ADST domains were scored to produce a developmental age in months and categorised into two possible outcomes: (1) normal and (2) monitor (for children requiring review over time but not necessarily intervention).

3. Social-emotional wellbeing

The parent report version of the Strengths and Difficulties Questionnaire (SDQ) was completed by parents to identify social-emotional problems in children and young people from 4 - 17 years of age. This tool was selected because it has been validated for use across cultures, is quick to administer and has demonstrated reasonable cross informant correlations, good internal consistency and correlation with Rutter scales and the Achenbach Child Behaviour checklist. [25-29] Translated SDQs were used if available (Arabic and Farsi), and the primary respondent was literate in their first language. Interpreters were briefed before assessments to ensure consistency between interpreters and translated SDQs.

The SDQ includes 25 items with 5 symptom scales to evaluate emotional symptoms,

conduct problems, hyperactivity and inattention, peer relations and prosocial

behaviour.[30] Scores were generated for each subscale and the Total Difficulties

219 (TD). High SDQ scores indicate increased risk of social-emotional problems. The

220 SDQ scores were classified into 3 categories: (1) normal, (2) borderline and (3)

abnormal. Children who scored in the abnormal or borderline ranges on the

Refugee Child Health clinical team or their GP.

developmental or social-emotional screening assessments were referred to the local

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226	4. Risk and protective factors
227	Risk and protective factors for health outcomes were assessed using a structured
228	interview (Text Box 2) and the Holmes and Rahe Social Readjustment Rating Scale
229	(SRRS).[31, 32] The SRRS was used to measure the impact of stressful life events
230	occurring in the previous 12 months, such as changes in family composition,
231	employment and stability of residence. Scores that were greater than 300 on the
232	scale indicate a high risk (over 80% chance) of developing a significant illness.[33,
233	34] As part of the structured interview parents were asked about their experience of
234	participating in the research and whether the study questionnaire was easy to
235	understand and respectful or produced any confusion or uncomfortable feelings.
236	
237	The underlying theoretical model for analysis of the cohort data is the bio-ecological
238	model of child health.[35] In keeping with this, risk and protective factors were
239	classified into: (1) child factors (age, gender, physical health on arrival, presence of
240	chronic disease, BMI), (2) family factors (family composition, parental disclosure of
241	trauma, time in refugee camp, region of origin) and (3) settlement factors (stressful
242	life events in last year, employment and study status, English language proficiency,
243	socio-economic resources, experience of discrimination and access to health care)
244	(Table 2).
245	

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246 Measurement schedule

The measurement schedule was as follows: General Practitioners conducted the 247 physical health examinations and pathology testing on all children shortly after arrival 248 (average 20.4 days; range 6 to 98 days), consistent with the model of care (within 249 250 the first year; Year 1 assessments). Research assessments were carried out by the 251 research team, which included RHNs and paediatric doctors. The first follow up 252 assessment occurred at Year 2 (average 13 months after arrival; range of 6-23 months) and the second follow up assessment at Year 3 (average 31 months after 253 254 arrival; range of 21-40 months). Developmental and social-emotional screening assessments were delayed until Years 2 and 3 to allow for a period of adjustment 255 and to reduce capturing immediate resettlement stress. 256

At Years 2 and 3 children aged 6 months to 5 years had developmental screening assessments using the Australian Developmental Screening Tool (ADST); children aged 4-17 years had social-emotional screening assessments using the Strengths and Difficulties Questionnaire (SDQ). Children aged 4 - 5 years were eligible for both screening assessments.[30,31]

Before finalising the measurement schedule, we conducted a small pilot study in 3
families. Based on these assessments and participant feedback, a few questions
were altered, repetitive questions were removed and the measurement instruments
were reduced in number to limit assessment at each time point to 8 hours,

266 conducted over two sessions for each child.

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Data management

An Access database was developed to capture the data for the study, including demographic, physical health, child development (ADST) and social-emotional health (SDQ) data and risk and protective factors (SRRS and structured interviews). Information was entered by RHNs.

Data Analysis

All data were analysed using SPSS version 22.0 using a predetermined analysis plan.[36] Categorical data were described with frequency percentages. Continuous

data were described with means and standard deviations (SD) and effect sizes

between groups calculated as the mean difference divided by the pooled SD.[37]

The data from the structured interviews of parents' research experience was

recorded categorically in Access, coded in SPSS and analysed using quantitative

methods.

Ethics

Ethics approval was provided by the Human Research Ethics Committee Northern Hospitals Network, South Eastern Sydney Illawarra Area Health Service (HREC Ref No 09/163). Informed consent to participate in the study was sought from parents with a professional health care interpreter present.

Findings to date

- **Recruitment and retention**
- In the 4-year period between May 2009 and April 2013, 86 refugee families arrived in
- the study region with a total number of 228 children aged 6 months to 15 years
- (Figure 1). The eligibility criteria for the study were met by 158 children; the main

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reason for ineligibility was that two children per family had been enrolled. Of the 158
eligible, 85 (54%) children were approached and 61 children were recruited for the
study (27% of all newly arrived children and 39% of all eligible children). The
remaining 73 children were not approached for recruitment due to limited availability
of interpreters for research purposes and part time research staff (n=52; 71%),
families relocating out of the area (n=13; 18%) and inability to contact families (n=8;
11%).

The enrolled sample was similar to the eligible population in terms of gender but the mean age (6 years; SD = 4 years) was younger than the eligible population (9 years; SD = 4.5 years) (Table 3), consistent with preferentially including the youngest two children in each family. The sample had similar proportions to the eligible population for the Eastern Mediterranean WHO region of origin (21% versus 26% respectively) but the South East Asian region was over-represented (43% versus 32%) and the African region under-represented (33% versus 42%). This reflected the availability of language specific interpreters available to facilitate recruitment during the study period.

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Primary respondents of the structured interviews were predominantly mothers (n=32; 62%) (Table 3). All children (100%) were assessed at Year 2 (n=61) between April 2010 – January 2014. At Year 3, 52 children were assessed, which represented a retention rate of 85%. Nine children could not have their Year 3 assessment within the study time frame due to study delays, resource constraints or relocation out of the area. These children were similar to the study sample in terms of gender, age, WHO region of origin, language spoken at home, prior education and employment of the primary respondent. Participant experience: The study was generally considered acceptable to parents. The majority found the questionnaires easy to answer (Year 2: 33/39, 85%; Year 3: 35/42, 83%) without being confusing (Year 2: 28/39, 72%; Year 3: 43/47, 91%) or raising uncomfortable feelings (Year 2: 37/37, 100%; Year 3: 36/39, 92%), and all parents found the research respectful. Management of the project The Research Implementation Committee managed the day-to-day operational aspects of the study and met monthly. A Project Management Committee with representatives from each of the partner organisations as well as policy and implementation agencies met quarterly for strategic oversight, reporting and feedback.

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333 Discussion

A growing body of research demonstrates that optimising development (including language and cognitive development, social-emotional and physical health) in early childhood has positive long term benefits including increasing children's intelligence. school achievement, employment, mental health and socio-economic status in adulthood.[38-43] Children from a refugee background are often exposed to significant levels of trauma and instability during the early years which increases their risk of poor developmental and social-emotional health outcomes.[44-49] The longitudinal cohort study described in this article was designed to utilise an existing high uptake model of care to access the newly arrived refugee population to measure health, developmental and socio-emotional wellbeing outcomes and examine a wide range of risk and protective factors.

Research in refugee populations may present specific challenges but studies such as this can ensure that services are evidence based, target refugee-specific needs and produce optimal outcomes. Refugee participation in research is important as exclusion may create systems of care directed at the 'mainstream', limiting the ability of research to reduce inequities in health.[50,51] This prospective cohort study provides the methodology to achieve this end but has faced a number of logistic difficulties. Recruitment was anticipated to be a challenge in establishing this cohort and was indeed low at 39% of eligible children. However participant refusal was lower than expected and occurred in only 15% of newly arrived families.

A fundamental challenge in conducting this study was that professional health care interpreters were expensive and availability was limited, especially for some new and emerging language groups (e.g. Amharic). The research team considered face to

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357 face interpreters essential to enable families to give informed consent and for 358 ongoing participation. Understandably interpreter services prioritised clinical 359 consultations over research requests, which led to lack of capacity to approach some families. The need for interpreters also increased the length of assessment time, 360 affecting maintaining the child's attention. Furthermore, some emerging local refugee 361 communities were so small that there were participant concerns regarding interpreter 362 confidentiality. 363 This study was limited by small sample size, but we offset this by investing in 364 365 effective retention strategies to minimise attrition. Attrition is more common in the early years of longitudinal studies and occurs for various reasons including 366

relocation, time constraints or loss of interest.[52] We expected amplification of this
effect in the refugee population due to cultural and language barriers, or precipitated
by the refugee experience, such as mistrust of researchers and concerns about the
results affecting immigration status. In contrast, once participants were recruited,
100% remained engaged at Year 2 and the majority (85%) at Year 3. Retention was

372 higher than in other local studies in vulnerable populations in which retention at $2\frac{1}{2}$

to 3 years ranged from 62.5% in an home visiting trial in a disadvantaged urban

374 community to 78% in both a refugee youth study and an urban birth cohort of

Aboriginal babies and their mothers.[16,52-54] The high retention in this study

376 reflects the considerable effort made by the research team to retain the sample with

377 specific retention strategies, particularly home visits, flexible timing of appointments

and willingness of the research team to assist families with any challenges

379 confronting them, including housing and education.

380 Measurement instrument selection is important and unfortunately developmental and
 381 social-emotional wellbeing screening tools have not been validated in refugee

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382	children. Children's scores on the developmental tool used in this study may require
383	careful interpretation due to the presentation of unfamiliar images used in the testing
384	kit and children's past exposure to play, literacy and numeracy materials (such as
385	writing their name and address, threading beads, knowing colours, using scissors).
386	Cultural and family practices also influence the usefulness of standardised tests.
387	Nonetheless it is almost impossible to develop 'culture-free' cognitive tools and there
388	is value in having generally applicable expectations and standards for children's
389	development.[55-58]
390	Any assessment is vulnerable to intrinsic error such as wanting to please the
391	researcher. This may be amplified in the refugee setting as parents may view the
392	child's performance as a reflection of their family and community and fear impact of
393	the child's results on their immigration status. This was the explicit reason for
394	conducting developmental screening assessments using mostly researcher
395	observed, play-based rather than parent reported skills.
396	This research is an example of 'action research' where researchers, parents, service
397	delivery agencies and government policy and implementation sectors work together
398	to improve refugee child health.[59,60] The interconnectedness with local resources
399	and infrastructure, rather than a separate vertical research-funded suite of
400	interventions, makes the implementation of future recommendations more likely to
401	be sustainable.
402	The use of clinician refugee nurses as researchers may present a tension between
403	having objective research staff at arm's-length from clinical care, with 'blinded'

researcher-clinicians embedded in existing service systems to maximise recruitment.

researchers completing follow-up assessments to minimise bias, as compared with

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Whilst the latter may impact on the "purity" of an observational longitudinal study, it allows for ethical research in communities in whom researchers would otherwise be passively observing and documenting unmet health needs. Participants are more likely to access care that the research identifies they require, as well as to remain engaged in the research, if there are close research-clinical linkages [61] Clinician-researchers can also serve as effective "bridges" between the research and practice communities and can facilitate both the development of clinically relevant research and the dissemination of evidence-based practice into routine clinical services.[62] It is important when using the researcher-clinician model that there is no inadvertent coercion to participate due to the close linkage between clinical care and research. [17-19, 51, 62]

418 Future plans

This longitudinal cohort study is the first of its kind in a refugee child population and demonstrates feasibility and acceptability to families of the measures employed. The establishment of this cohort provides the opportunity for the research team to gather valuable data about the early settlement experience, risk and protective factors and long term health, developmental and social-emotional wellbeing outcomes in refugee children. Further funding is being sought to continue follow up with the existing cohort of refugee children and to increase the sample size by including other jurisdictions.

The next phase will be to investigate how these risk and protective factors are
related to health and wellbeing outcomes in refugee children. The involvement of key

429 service providers and policy makers in this study aims to ensure optimal translation

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430 of findings to policy and service development. This is vital so that refugee children at

risk of adverse health and wellbeing outcomes are identified early after arrival and

and can access the interventions they require.

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Halvert-Bruce.

440 Authors' Contributions

Karen Zwi conceived of the study, and provided leadership in its design and coordination, conceptualised the analysis and drafted the manuscript. Santuri Rungan performed statistical analysis and helped draft the manuscript. Susan Woolfenden participated in the study design and reviewed the manuscript. Katrina Williams participated in the study design and reviewed the manuscript. Lisa Woodland participated in study design and coordination, performed statistical analysis and reviewed the manuscript. All authors read and approved the final manuscript.

Competing Interests

The authors declare that they have no competing interests.

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Data Sharing 456

- Since this article describes the establishment of a longitudinal cohort and early 457
- ut su. 458 findings, full results will be submitted for peer reviewed publication in due course.
- 459 The authors are willing to share unpublished data with interested parties.

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Figure 1: Recruitment and retention

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665	Table 1: Measurement of child outcome measures, by age group
005	ruble 1. medsurement of clinic outcome medsures, by uge group

Outcome	Assessment	Timing of assessment	Rationale
Physical health (Children aged 6 months to 17 years)	 Pathology tests Full blood count, renal and liver function tests Ferritin level Vitamin D level Serology for hepatitis B, hepatitis C, HIV, syphilis, schistosomiasis, strongyloides and immunity to rubella, measles and mumps. Malaria thin and thick smear, and a rapid diagnostic test. QuantiFERON TB Gold (QFN) 	On arrival	Child health is associated wit health in later life[38]
	Child's height, weight and body mass index (BMI)	On arrival Year 2 Year 3	Underweight is associated wit poor school performance[3 39] Obesity is associated wit
			several health problems[39]
Development* (Children aged 6 months to 5 years)	Australian Developmental Screening Tool (ADST): Personal/Social Language Cognitive Fine Motor Gross Motor	Year 2 Year 3	Child development associated wit school readiness, social development and later academic achievement[4 41]
Social- emotional wellbeing (Children aged 4 years to 17 years)	Strengths and Difficulties Questionnaire (SDQ)	Year 2 Year 3	Social- emotional wellbeing associated wit positive health and education outcomes[42, 43]

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669 Table 2: Measurement of risk and protective factors

	Risk and protective factors	Measurement instrument	Timing of Assessment
Child factors	 age gender physical health on arrival presence of chronic disease BMI 	 physical health assessment structured questionnaire 	On arrival Year 2 Year 3
Family factors	 family composition parental disclosure of trauma time in refugee camp region of origin 	 Social Readjustment Ratings Scale (SRRS) structured questionnaire 	Year 2 Year 3
Settlement factors	 stressful life events in last year employment and study status English language proficiency socio-economic resources experience of discrimination access to health care 	 Social Readjustment Ratings Scale (SRRS) structured questionnaire 	Year 2 Year 3

Table 3: Demographic details of eligible population, study sample and

respondent characteristics

			Eligible Children (n=158)		Study Sample (n=61)
Characteristics of C	hild		· · · ·		
		Number	Percentage	Number	Percentage
Gender	Male	78	49%	29	48%
	Female	80	51%	32	52%
Mean age on arrival (years)		9		6	
WHO Region (County of origin)	African DR Congo Ethiopia Kenya Malawi Burundi Togo	66	42%	20 12 2 2 2 1 1	33%
	Eastern Mediterranean Iran Iraq Lebanon	41	26%	13 5 5 3	21%
	Europe	1	<1%	0	0%
	South East Asia Burma	50	32%	28 28	46%
Languages Spoken at Home	Amharic			2	3%
	Arabic			8	13%
	Burmese			13	22%
	Chin Senthang			2	3%
	English	-		4	7%
	Farsi			5	8%
	French			2	3%
	Karen			10	17%
	Karenni			3	5%
	Kirundi			3	5%
	Swahili			8	13%
Characteristics of P					
Gender (n=60)	Male			23	38%
	Female			37	62%
Prior Education (n=54)	None			4	7%
	Primary			15	27%
	Secondary			23	43%
	University			9	17%
Employment in home country (n=53)	Trade Professional			3 17	6% 32%
(Semi-skilled/ unskille	d		19	36%
	Voluntary			5	9%
	Unemployed			12	23%
Characteristics of P	artner of Primary Res	pondent			
Gender (n=41)	Male	-		18	44%
	Female			23	56%
Prior Education (n=34)	None			1	3%
	Primary			11	32%
	Secondary			16	47%

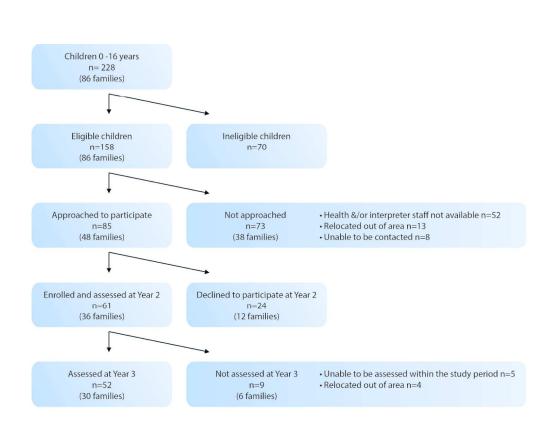
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	University Trade	6 0	18% 0%
mployment in	Professional	11	32%
ome country =34)			0270
	Semi-skilled/ unskilled	16	47%
	Voluntary	3	9%
	Unemployed	4	12%

Page 37 of 41

1 2		
3 4	676	Text Box 1
5 6 7	677	Retention strategies to minimise attrition included:
8 9 10	678	conducting a small pilot study to ensure that tools and questionnaires were
11 12	679	acceptable to families;
13 14	680	ensuring phone-calls and interviews were scheduled at convenient times for
15 16	681	families;
17 18 19	682	 conducting assessments in the participants' homes;
20 21	683	employing multiple call back strategies to make initial contact and to convert
22 23	684	contact into a completed interview;
24 25 26	685	conducting interviews which engage and interest respondents;
27 28	686	 providing feedback to parents about the outcomes of screening;
29 30	687	• undertaking to organise further services as required as well as support to access
31 32	688	appointments;
33 34 35	689	encouraging community support through regular feedback to local community
36 37	690	organisations and settlement services, participation in community health
38 39	691	promotion activities and written information;
40 41	692	• working closely with GPs and settlement services who could provide updated
42 43 44	693	contact details for families.
45 46	694	
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701	Text Box 2
702	The structured interview information includes:
703	• need for and access to health services over the previous three months, including
704	health problems/injuries experienced by the child; visits to the GP and other
705	health professionals; presentations to Emergency Department (ED) or hospital;
706	immunisation or preventive health activities;
707	access to socio-economic resources (such as salaries, grants and pensions);
708	access to community support (such as neighbours, religious and/or community
709	organisations);
710	• family stressors and life events post arrival (including moving house or death of
711	family members);
712	exposure to perceived racism or other forms of discrimination;
713	• experience of the study questionnaire (whether it was easy to understand,
714	respectful, or produced any confusion or uncomfortable feelings)
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Section/Topic	ltem #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in	1
		the title or the abstract	
		(b) Provide in the abstract an informative and balanced	3
		summary of what was done and what was found	
Introduction	1		
Background/rationale	2	Explain the scientific background and rationale for the	5-6
		investigation being reported	
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including	6-7
		periods of recruitment, exposure, follow-up, and data	
		collection	
Participants	6	(a) Give the eligibility criteria, and the sources and methods of	7
		selection of participants. Describe methods of follow-up	
		(b) For matched studies, give matching criteria and number of	n/a
		exposed and unexposed	
Variables	7	Clearly define all outcomes, exposures, predictors, potential	9-12; Table 1 (pg 13) and
		confounders, and effect modifiers. Give diagnostic criteria, if	Table 2 (pg 18)
		applicable	
Data sources/	8*	For each variable of interest, give sources of data and details	12; Table 1 (pg 13) and
measurement		of methods of assessment (measurement). Describe	Table 2 (pg 18)
		comparability of assessment methods if there is more than one	
		group	
Bias	9	Describe any efforts to address potential sources of bias	18
Study size	10	Explain how the study size was arrived at	18; Figure 1
Quantitative	11	Explain how quantitative variables were handled in the	17-18
variables		analyses. If applicable, describe which groupings were chosen	
		and why	
Statistical methods	12	(a) Describe all statistical methods, including those used to	17-18
		control for confounding	
		(b) Describe any methods used to examine subgroups and	n/a as this cohort study
		interactions	presents cohort creation,
			methods, baseline data
			and future plans
		(c) Explain how missing data were addressed	n/a
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a
D IV.			170
Results	60 ⁺		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg	18; Figure 1
		numbers potentially eligible, examined for eligibility, confirmed	
		eligible, included in the study, completing follow-up, and	
		analysed	

Research Checklist STROBE 2007 (v4) Statement for cohort studies

	- <u>r</u>		
		(b) Give reasons for non-participation at each stage	18
		(c) Consider use of a flow diagram	Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential	18-19; Table 3 (pg 20)
		confounders	
		(b) Indicate number of participants with missing data for each variable of interest	Table 3 (pg 20)
		(c) Summarise follow-up time (eg, average and total amount)	3, 8, 16-17
Outcome data	15*	Report numbers of outcome events or summary measures over time	n/a
Main results	16	(<i>a</i>) Give unadjusted estimates and, if applicable, confounder- adjusted estimates and their precision (eg, 95% confidence	n/a
		interval). Make clear which confounders were adjusted for and	
		why they were included	
		(b) Report category boundaries when continuous variables	n/a
		were categorized	.,
		(c) If relevant, consider translating estimates of relative risk	n/a
		into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and	n/a
		interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	22-25
Limitations			23-25
Interpretation	20	Give a cautious overall interpretation of results considering	25-26
		objectives, limitations, multiplicity of analyses, results from	
		similar studies, and other relevant evidence	
Generalisability	21	Discuss the generalisability (external validity) of the study	26
		results	
Other information			
Funding	22	Give the source of funding and the role of the funders for the	27
		present study and, if applicable, for the original study on which	
		the present article is based	

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.