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Title

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

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Abstract

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.

Method and design: General Practitioners conducted health and pathology 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-representation of African refugees as compared to the eligible population. Parents 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 child population is feasible and acceptable, and retention rates can be high. The

establishment of this cohort provides the opportunity to gather valuable data about the early settlement experience, risk and protective factors and long term health and wellbeing outcomes in refugee children. These are necessary to identify refugee children in need of additional support and guide future service delivery.

Key Words: Refugee, children, development, cohort, longitudinal, health, wellbeing, Community child health, PAEDIATRICS

Strengths and limitations

- a strength in the study design was recruitment through an established high uptake population-based screening program for refugees, and utilising trusted nurses to enrol families and provide ongoing care
- the study demonstrated feasibility and acceptability in examining a wide range of risk and protective factors and measuring health and wellbeing outcomes over 3 years in a population known to be challenging to follow up
- a key strength was the consideration of many important factors in conducting ethical research in this highly vulnerable population, creating the potential to add to the evidence base, gather valuable data, and contribute to policy and practice change
- we sought to offset an important limitation, small sample size, by investing in retention strategies to minimise attrition, which were effective once participants were recruited
- limited availability of professional health care interpreters was a key challenge in recruitment and the need for interpreters also increased the length of assessment time and study costs

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,

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.

Purpose

A cohort of refugee children was created to investigate the physical health, development and social-emotional wellbeing in refugee children and the impact of risk and protective factors on these outcomes over their first 3 years in Australia. This article describes the methodology used to conduct a longitudinal cohort study in refugee children in a regional community, including sample characteristics, and recruitment and retention strategies and their effectiveness.

Methods and design

Setting

The Illawarra region of New South Wales (NSW), Australia, has a long history of refugee resettlement including European communities following World War II, the Vietnamese community in the 1970s and the Serbian, Croatian and Bosnian communities in the 1990s. The most recent arrivals are from African countries, Burma and the Middle East. (1) In this region, a collaborative nurse-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. (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)

Measurement schedule

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

The final measurement schedules 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 Refugee Health Nurse and paediatric doctors. The first follow-up assessment occurred at Year 2 (average 12.5 months after arrival; range of 6-23 months) and the second follow-up assessment at Year 3 (average 30.6 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. 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); the school-aged children (4-17 years) had social-emotional screening assessments using the Strengths and Difficulties Questionnaire (SDQ). (38,39) Key outcomes for the study were physical health, child development (ADST) and social-emotional health (SDQ) (Table 1).

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-γ 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 Year 2 and Year 3.

2. Development

The Australian Developmental Screening Test (ADST) tool was selected to assess development in preschool children because it was a standardised, individually administered, objective and play-based developmental screening test. (38) 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). (41) 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 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

(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.

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)

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)

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 $P<0.05$.

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 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).

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.

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.

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.

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 met quarterly for strategic oversight, reporting and feedback. Policy and implementation agencies are involved and will inform the policy translation phase.

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 IQ, school achievement, employment, mental health and socio-economic status in adulthood. (52-57) It is this evidence that drives the need to identify those children in need of additional support as early as possible and to design appropriate screening programs and early intervention services. 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. (58-63) This longitudinal cohort study was designed to utilise an existing

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 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

and infrastructure, rather than a separate vertical research-funded suite of interventions, makes the implementation of future recommendations more likely to be sustainable. However this study design presents a tension between optimal research, with research staff at arm's-length from clinical care and different researchers completing follow-up assessments to minimise bias, and research using known clinicians embedded in existing service systems to maximise recruitment. Ethical research should ensure there is no inadvertent coercion to participate, which may be more difficult if clinical care and research are highly linked. (64-68) On the other hand, participants are more likely to access care that the research identifies they require if there are close research-clinical linkages. (69)

Attrition is more common in the early years of longitudinal studies and occurs for various reasons including relocation, time constraints or loss of interest. (58,70) 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% remain engaged at Year 2 and the majority (85%) at Year 3; retention was higher than in other local studies in vulnerable populations. The refugee youth study retained 78% at 3 years (33). Retention an urban birth cohort of Aboriginal babies and their mothers was 77.4% at 3 years; the MESCH sustained home visiting trial in a disadvantaged urban community retained only 62.5% at 30 months. (70-72) The high retention in this study reflects the considerable effort made by the research team to retain the sample with specific retention strategies, particularly home visits, flexible timing of visits and willingness of the research team to assist families with any challenges confronting them, including housing and education.

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

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-

emotional distress in this context and does not specifically assess aspects unique to the refugee experience such as relocation, food insecurity, trauma exposure and safety. (58) These issues could be considered for an adapted version of the SDQ for refugee children, but at the risk of creating a different 'norm'.

A fundamental challenge in conducting this study was that professional health care interpreters were expensive and availability was limited due to face to face interpreters not being available for some language groups (e.g. Amharic) and interpreter services prioritising clinical consultations over research requests. Yet interpreters were considered essential for families to give informed consent and for ongoing participation. The need for interpreters also increased the length of assessment time, affecting maintaining the child's attention, but prior interpreter training was rarely possible because of availability constraints. Furthermore some emerging local refugee communities were so small that there were concerns regarding interpreter confidentiality.

This research can be described as 'action research' where the engaged partners include researchers, service delivery agencies and government policy and implementation sectors, and the researchers are striving to improve health and service delivery for participants. (77,78) Whilst this 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. An interesting consequence of such research, particularly since it is based in one region, may be that awareness of child development and social-emotional health is highlighted to service delivery staff and may change their practice in the longer term. 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 treatments into routine clinical services. (68, 69)

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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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 drafted the manuscript. Sue 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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Text Box 1

The **structured interview information** includes:

- need for and access to health services over the previous three months, including health problems/injuries experienced by the child; visits to the GP and other health professionals; presentations to Emergency Department (ED) or hospital; immunisation or preventive health activities;
- access to socio-economic resources (such as salaries, grants and pensions);
- access to community support (such as neighbours, religious and/or community organisations);
- family stressors and life events post arrival (including moving house or death of family members);
- exposure to perceived racism or other forms of discrimination;
- experience of the study questionnaire (whether it was easy to understand, respectful, produced any confusion or uncomfortable feelings)

Text Box 2

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 access 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.

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Figure 1: Flowchart of recruitment and retention

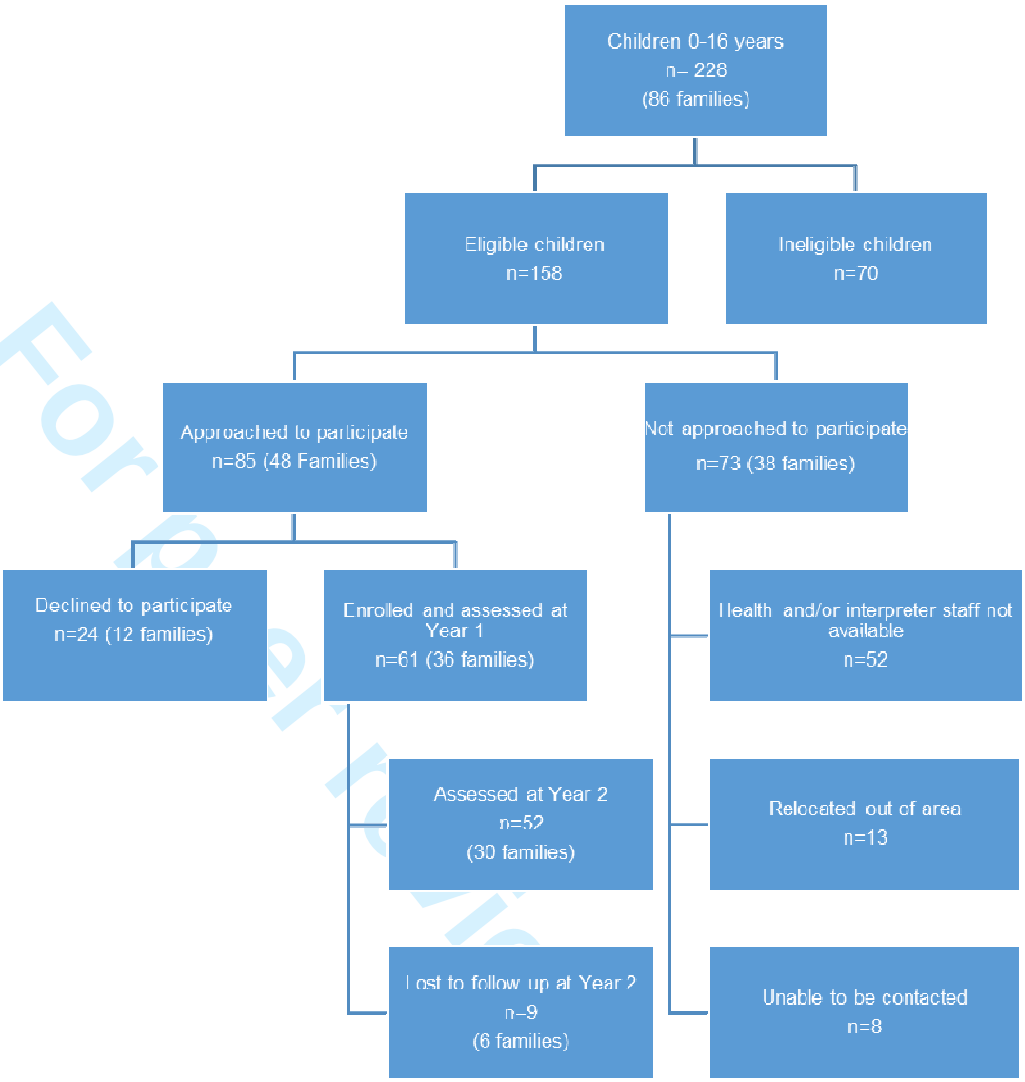

Table 1: Measurement of child outcome measures, by age group

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)	On arrival	Child health is associated with health in later life[52]
	Child's height, weight and body mass index (BMI)	Child's height, weight and body mass index (BMI)	On arrival Year 2 Year 3	Underweight is associated with poor school performance[52,53] Obesity is associated with several health problems[53]
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

				and educational outcomes[56,57]

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 Child					
		Number	Percentage	Number	Percentage
Gender	Male	78	49%	29	48%
	Female	80	51%	32	52%
Mean age on arrival (years)		9		4	
WHO Region (County of origin)	**African**	66	42%	20	33%
	DR Congo			12	
	Ethiopia			2	
	Kenya			2	
	Malawi			2	
	Burundi			1	
	Togo			1	
	Eastern Mediterranean	41	26%	13	21%
	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			10	17%
	Karenni			3	5%
	Kirundi			3	5%
	Swahili			8	13%
Characteristics of Primary Respondent					
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%
Characteristics of Partner of Primary Respondent					
Gender (n=41)	Male			18	44%
	Female			23	56%
Prior Education (n=34)	None			1	3%
	Primary			11	32%
	Secondary			16	47%

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

Research Checklist STROBE 2007 (v4) Statement for cohort studies

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) 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	(*a*) 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	(*a*) 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 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 numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	13-14

		(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	(*a*) 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.

BMJ Open

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

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Title

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Abstract

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 a regional part of Australia and aged 6 months to 15 years one month were recruited between 2009 and 2013 and 85% followed for 31 months on average.

Method and design: General Practitioners conducted health and pathology examinations shortly after arrival. Additional follow up assessments were conducted by the research team at an average of 13 months after arrival for the first (Year 2) and 31 months for the second (Year 3) assessment. Children under 5 years had developmental and children aged 4-17 years had social-emotional screening. Families were assessed for risk and protective 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-representation of African refugees as compared to the eligible population. Parents reported the research was respectful.

Future plans: This study demonstrates that a longitudinal cohort study in a refugee child population is feasible and acceptable, and retention rates can be high. The

establishment of this cohort provides the opportunity to analyse valuable data about the early settlement experience, risk and protective factors and long term health and wellbeing outcomes in refugee children.

Key Words: Refugee, children, development, cohort, longitudinal, health, wellbeing, Community child health, PAEDIATRICS

Strengths and limitations

- a strength in the study design was recruitment through an established high uptake population-based screening program for refugees, and utilising trusted nurses to enrol families and provide ongoing care
- the study demonstrated feasibility and acceptability in examining a wide range of risk and protective factors and measuring health and wellbeing outcomes over 2-3 years in a population known to be challenging to follow up
- a key strength was the consideration of many important factors in conducting ethical research in this highly vulnerable population, creating the potential to add to the evidence base, gather valuable data, and contribute to policy and practice change
- we sought to offset an important limitation, small sample size, by investing in retention strategies to minimise attrition, which were effective once participants were recruited
- limited availability of professional health care interpreters was a key challenge in recruitment and the need for interpreters also increased the length of assessment time and study costs

Introduction

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 below 25 years. (1) Children from a refugee background often arrive in Australia with unmet health, developmental and socioemotional needs due to a combination of factors including forced migration, suboptimal living conditions and limited access to healthcare. (2,3) Refugee children are particularly at risk of adverse developmental and mental health outcomes because of the refugee experience itself and the process of resettlement. (4-6) However, whilst routine health screening on arrival is recommended by the Royal Australasian College of Physicians (RACP) and detects many significant and treatable health problems, the need for routine screening of developmental or social-emotional wellbeing in the period after resettlement has not been formally examined in cross sectional or prospective studies due to challenges in conducting such studies in refugee populations. (7-13)

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. (14-16) The Australian National Health and Medical Research Council (NHMRC) provides recommendations for research in vulnerable communities, including that such research be descriptive in nature, longitudinal in design, collect evidence to effect change and be underpinned by an ethical theoretical framework that guides design and implementation to produce robust data on health and wellbeing". (17-19)

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. (20,21) 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. (20,21) 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. (16)

For this research, a cohort of refugee children was created in a regional community in Australia. This article describes the methodology used to conduct this longitudinal cohort study, and describes sample characteristics, and the effectiveness of recruitment and retention strategies employed. The study was designed to explore 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.

Methods and design

Setting

The Illawarra region of New South Wales (NSW), Australia, has a long history of refugee resettlement including European communities following World War II, the Vietnamese community in the 1970s and the Serbian, Croatian and Bosnian communities in the 1990s. The most recent arrivals are from African countries, Burma and the Middle East. (1) In this region, a collaborative nurse-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. 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

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. (Figure 1)

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.

At Years 2 and 3 children aged 6 months to 5 years old 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. (24,25) Key outcomes for the study for physical health, child development (ADST) and social-emotional health (SDQ) are outlined in Table 1.

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 body mass index (BMI)		On arrival Year 2 Year 3	Underweight is associated with poor school performance[38,39] Obesity is associated with several health problems[39]
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[40,41]
Social-emotional wellbeing		Strengths and Difficulties Questionnaire (SDQ)	Year 2 Year 3	Social-emotional wellbeing associated with positive health and educational outcomes[42,43]

*Note: children aged 4-5 years were eligible for both the Australian Developmental Screening Tool (ADST) and the Strengths and Difficulties Questionnaire (SDQ)

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).

Text Box 1

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 access 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.

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

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-γ 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.

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).

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. (29-33) 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. (25) Scores were generated for each subscale and the Total Difficulties (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.

4. Risk and protective factors

Risk and protective factors were assessed using a structured interview (Text Box 2) and the Holmes and Rahe Social Readjustment Rating Scale (SRRS). (24) The 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)

Text Box 2

The **structured interview information** includes:

- need for and access to health services over the previous three months, including health problems/injuries experienced by the child; visits to the GP and other health professionals; presentations to Emergency Department (ED) or hospital; immunisation or preventive health activities;
- access to socio-economic resources (such as salaries, grants and pensions);
- access to community support (such as neighbours, religious and/or community organisations);
- family stressors and life events post arrival (including moving house or death of family members);
- exposure to perceived racism or other forms of discrimination;
- experience of the study questionnaire (whether it was easy to understand, respectful, or produced any confusion or uncomfortable feelings)

Before finalising the measurement schedule, we conducted a small pilot study in 3 families to ensure that tools and questionnaires were practical. Based on these assessments and participant feedback, a few questions were altered, repetitive questions were removed and the study measurement instruments were reduced in number to limit questionnaire completion and assessment at each time point to 8 hours, conducted over two sessions for each child. We also developed a recruitment strategy of preferentially recruiting the youngest two children in each family.

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.

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 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.

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

		Eligible Children (n=158)		Study Sample (n=61)	
Characteristics of Child					
		Number	Percentage	Number	Percentage
Gender	Male	78	49%	29	48%
	Female	80	51%	32	52%
Mean age on arrival (years)		9		4	
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 Primary Respondent					
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%
Characteristics of Partner of Primary Respondent					
Gender (n=41)	Male			18	44%
	Female			23	56%
Prior Education (n=34)	None			1	3%
	Primary			11	32%
	Secondary			16	47%

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

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, between March 2013 – August 2014, 52 children from 30 families were assessed, which represented a retention rate of 85%. Five of these children could not have their Year 3 assessment within the study time frame. 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, 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.

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 IQ, 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) This longitudinal cohort study 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 presented 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, which was expected, occurred in only 15% of those approached. 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). Understandably interpreter services prioritised clinical consultations over research requests.

This study was limited by small sample size, but we offset this by investing in effective retention strategies to minimise attrition. Attrition is more common in the early years of longitudinal studies and occurs for various reasons including relocation, time constraints or loss of interest. (5744,52) 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 higher than in other local studies in vulnerable populations in which retention at 2½ to 3 years ranged from 62.5% in an home visiting trial in a disadvantaged urban 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 reflects the considerable effort made by the research team to retain the sample with specific retention strategies, particularly home visits, flexible timing of visits and willingness of the research team to assist families with any challenges confronting them, including housing and education.

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

scores in relation to language and interpretation of unfamiliar images used in the testing kit and exposure to play, literacy and numeracy materials (such as writing name and address, threading beads, knowing colours, using scissors). Cultural and family practices also influence the usefulness of standardised tests but it is almost impossible to develop 'culture-free' cognitive tools and there is value in having generally applicable expectations and standards for children's development. (55-58)

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

A fundamental challenge in conducting this study was that professional health care interpreters were expensive and availability was limited due to face to face interpreters not being available for some language groups and interpreter services prioritising clinical consultations over research requests. Yet interpreters were considered essential for families to give informed consent and for ongoing participation. The need for interpreters also increased the length of assessment time, affecting maintaining the child's attention. Furthermore some emerging local refugee communities were so small that there were concerns regarding interpreter confidentiality.

This research can be described as 'action research' where the engaged partners include researchers, service delivery agencies and government policy and implementation sectors, and the researchers are striving to improve health and

service delivery for participants using an existing collaborative model of care to access families and provide ongoing care. (59,60) 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 and infrastructure, rather than a separate vertical research-funded suite of interventions, makes the implementation of future recommendations more likely to be sustainable. However this study design presents a tension between optimal research, with research staff at arm's-length from clinical care and different researchers completing follow-up assessments to minimise bias, and research using known clinicians embedded in existing service systems to maximise recruitment. Whilst this 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 if there are close research-clinical linkages. (61) However, rethical research should ensure there is no inadvertent coercion to participate, which may be more difficult if clinical care and research are highly linked. (17-19,51,62)

An interesting consequence of such research, particularly since it is based in one 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)

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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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 drafted 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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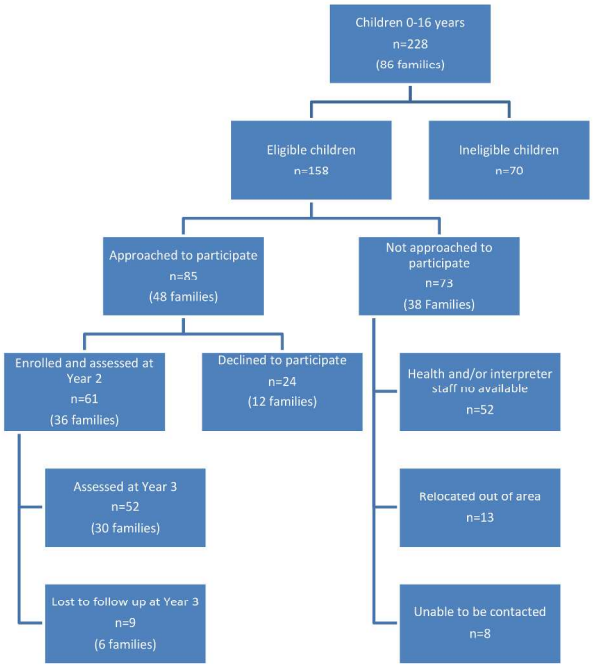

Figure 1: Flowchart of recruitment and retention
Figure 1
254x190mm (300 x 300 DPI)

Research Checklist STROBE 2007 (v4) Statement for cohort studies

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) 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	6~~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	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	7-8
		(*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; Table 1 and Table 2
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; Figure 1
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	(*a*) 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 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 numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	13-14; Figure 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	123-14 Table 1; Table 3
		(b) Indicate number of participants with missing data for each variable of interest	n/a13
		(c) Summarise follow-up time (eg, average and total amount)	143
Outcome data	15*	Report numbers of outcome events or summary measures over time	13-14; Table 1 and Table 2
Main results	16	(*a*) 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/aTable 3
Discussion			
Key results	18	Summarise key results with reference to study objectives	124-148
Limitations			15-17 19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-2015-19 Discussion
Generalisability	21	Discuss the generalisability (external validity) of the study results	15-2015-16 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	1921

*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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Title

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

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Abstract

Purpose: Few studies explore the long term health and wellbeing of refugee children. A longitudinal cohort of refugee children was created to determine health and wellbeing outcomes over time. This article describes the methodology used to conduct this study, including sample characteristics and effectiveness of recruitment and retention strategies.

Participants: Newly arrived refugee children settling in a regional part of Australia aged 6 months to 15 years were recruited between 2009 and 2013 and 85% followed for 31 months on average.

Method and design: General Practitioners conducted health and pathology examinations shortly after arrival. Additional follow up assessments were conducted by the research team at an average of 13 months after arrival for the first (Year 2) and 31 months for the second (Year 3) assessment. Children under 5 years had developmental and children aged 4-17 years had social-emotional screening. Families were assessed for risk and protective factors using a structured interview and the Social Readjustment Ratings Scale (SRRS). Parent 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-representation of African refugees as compared to the eligible population. Parents reported that the research was respectful.

Future plans: This study demonstrates that a longitudinal cohort study in refugee children is feasible and acceptable, and retention rates can be high. The

establishment of this cohort provides the opportunity to analyse valuable data about the early settlement experience, risk and protective factors and long term health and wellbeing outcomes in refugee children. These are necessary to identify refugee children in need of additional support and to guide future service delivery.

Key Words: Refugee, children, development, cohort, longitudinal, health, wellbeing, Community child health, PAEDIATRICS

Strengths and limitations

- a strength in the study design was recruitment through an established high uptake population-based screening program for refugees, and utilising trusted nurses to enrol families and provide ongoing care
- the study demonstrated feasibility and acceptability in examining a wide range of risk and protective factors and measuring health and wellbeing outcomes over 2-3 years in a population known to be challenging to follow up
- a key strength was the consideration of many important factors in conducting ethical research in this highly vulnerable population, creating the potential to add to the evidence base, gather valuable data, and contribute to policy and practice change
- we sought to offset an important limitation, small sample size, by investing in retention strategies to minimise attrition, which were effective once participants were recruited
- limited availability of professional health care interpreters was a key challenge in recruitment and the need for interpreters also increased the length of assessment time and study costs

Introduction

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 below 25 years.[1] Children from a refugee background often arrive in Australia with unmet health, developmental and social-emotional needs due to a combination of factors including forced migration, suboptimal living conditions and limited access to healthcare.[2, 3] Refugee children are particularly at risk of adverse developmental and mental health outcomes because of the refugee experience itself and the process of resettlement.[4-6] Routine health screening on arrival is recommended by the Royal Australasian College of Physicians (RACP) and detects many significant and treatable health problems. However the need for routine screening of developmental or social-emotional wellbeing in the period after resettlement has not been formally examined in cross sectional or prospective studies due to challenges in conducting such studies in refugee populations.[7-13]

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.[14-16] The Australian National Health and Medical Research Council (NHMRC) provides recommendations for research in vulnerable communities, including that such research is descriptive in nature, longitudinal in design, collects evidence to effect change and is underpinned by an ethical theoretical framework that guides design and implementation to produce robust data on health and wellbeing.[17-19]

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.[20, 21] The Longitudinal Study of Australian Children (LSAC) does not include sufficient numbers of 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.[20, 21] Only one longitudinal study of refugee youth has been conducted in Australia and the outcome was limited to self-rated wellbeing.[16]

This article describes the methodology used to conduct a longitudinal cohort study of refugee children in a regional community in Australia, including sample characteristics, and the effectiveness of recruitment and retention strategies employed. The purpose of this cohort was to explore 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.

Methods and design

Setting

The Illawarra region of New South Wales (NSW), Australia, has a long history of refugee resettlement including European communities following World War II, the Vietnamese community in the 1970s and the Serbian, Croatian and Bosnian communities in the 1990s. The most recent arrivals are from African countries,

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

recruit for research purposes. If obtained, the family was contacted for follow up assessments which 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. (Figure 1)

Given the importance of maintaining follow up in this cohort, a number of strategies to minimise attrition were employed (Text Box 1).

Measurement instruments

Key outcomes for the study were physical health, child development and social-emotional wellbeing (Table 1).

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)). 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 diagnostic test. All children had tuberculosis screening using an interferon-γ release assay, QuantiFERON TB Gold (QFN). Low ferritin levels (<20micrograms/litre) were used as a marker of iron deficiency. Vitamin D levels were defined as sufficient (50-230nmol/L), mild (26-50nmol/L), moderate (12.5-25nmol/L) and severe (<12.5nmol/L) deficiency. [8] Anthropometric measurements were repeated at Years 2 and 3.

2. Development

The Australian Developmental Screening Test (ADST) was selected to assess development in younger children because of its properties as a standardised, individually administered, objective and play-based developmental screening test. [24] The tool assesses five domains of development (language, cognitive skills, fine motor skills, personal/social skills and gross motor skills), and was administered by the RHN playing with the child and requesting information from the parent over approximately 30 minutes. Using published modified diagnostic criteria, specificity and sensitivity of ADST scores correlate well with the gold standard Griffiths Mental

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 (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. 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.

4. Risk and protective factors

Risk and protective factors for health outcomes were assessed using a structured interview (Text Box 2) and the Holmes and Rahe Social Readjustment Rating Scale (SRRS).[31, 32] The SRRS was used to measure the impact of stressful life events occurring in the previous 12 months, such as changes in family composition, employment and stability of residence. Scores that were greater than 300 on the scale indicate a high risk (over 80% chance) of developing a significant illness.[33, 34] 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.

The underlying theoretical model for analysis of the cohort data is the bio-ecological model of child health.[35] In keeping with this, risk and protective factors were classified into: (1) child factors (age, gender, physical health on arrival, presence of chronic disease, BMI), (2) family factors (family composition, parental disclosure of trauma, time in refugee camp, region of origin) and (3) 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).

Measurement schedule

The 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 RHNs 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.

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, conducted over two sessions for each child.

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

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.

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.

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

face interpreters essential to enable families to give informed consent and for ongoing participation. Understandably interpreter services prioritised clinical 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, affecting maintaining the child's attention. Furthermore, some emerging local refugee communities were so small that there were participant concerns regarding interpreter confidentiality.

This study was limited by small sample size, but we offset this by investing in effective retention strategies to minimise attrition. Attrition is more common in the early years of longitudinal studies and occurs for various reasons including 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 higher than in other local studies in vulnerable populations in which retention at 2½ to 3 years ranged from 62.5% in an home visiting trial in a disadvantaged urban 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 reflects the considerable effort made by the research team to retain the sample with specific retention strategies, particularly home visits, flexible timing of appointments and willingness of the research team to assist families with any challenges confronting them, including housing and education.

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

children. Children's scores on the developmental tool used in this study may require careful interpretation due to the presentation of unfamiliar images used in the testing kit and children's past exposure to play, literacy and numeracy materials (such as writing their name and address, threading beads, knowing colours, using scissors). Cultural and family practices also influence the usefulness of standardised tests. Nonetheless it is almost impossible to develop 'culture-free' cognitive tools and there is value in having generally applicable expectations and standards for children's development.[55-58]

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

This research is an example of 'action research' where researchers, parents, service delivery agencies and government policy and implementation sectors work together to improve refugee child health.[59,60] The interconnectedness with local resources and infrastructure, rather than a separate vertical research-funded suite of interventions, makes the implementation of future recommendations more likely to be sustainable.

The use of clinician refugee nurses as researchers may present a tension between having objective research staff at arm's-length from clinical care, with 'blinded' researchers completing follow-up assessments to minimise bias, as compared with researcher-clinicians embedded in existing service systems to maximise recruitment.

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]

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

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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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

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

Figure 1: Recruitment and retention

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Table 1: Measurement of child outcome measures, by age 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 with health in later life[38]
	Child's height, weight and body mass index (BMI)	On arrival Year 2 Year 3	Underweight is associated with poor school performance[38, 39] Obesity is associated with 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 with school readiness, social development and later academic achievement[40, 41]
Social-emotional wellbeing (Children aged 4 years to 17 years)	Strengths and Difficulties Questionnaire (SDQ)	Year 2 Year 3	Social-emotional wellbeing associated with positive health and educational outcomes[42, 43]

***Note:** children aged 4-5 years were eligible for both the Australian Developmental Screening Tool (ADST) and the Strengths and Difficulties Questionnaire (SDQ)

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 Child					
		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**	66	42%	20	33%
	DR Congo			12	
	Ethiopia			2	
	Kenya			2	
	Malawi			2	
	Burundi			1	
	Togo			1	
	Eastern Mediterranean	41	26%	13	21%
	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			10	17%
	Karenni			3	5%
	Kirundi			3	5%
	Swahili			8	13%
Characteristics of Primary Respondent					
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%
Characteristics of Partner of Primary Respondent					
Gender (n=41)	Male			18	44%
	Female			23	56%
Prior Education (n=34)	None			1	3%
	Primary			11	32%
	Secondary			16	47%

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

Text Box 1

Retention strategies to minimise attrition included:

- 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 access 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.

Text Box 2

The **structured interview information** includes:

- need for and access to health services over the previous three months, including health problems/injuries experienced by the child; visits to the GP and other health professionals; presentations to Emergency Department (ED) or hospital; immunisation or preventive health activities;
- access to socio-economic resources (such as salaries, grants and pensions);
- access to community support (such as neighbours, religious and/or community organisations);
- family stressors and life events post arrival (including moving house or death of family members);
- exposure to perceived racism or other forms of discrimination;
- experience of the study questionnaire (whether it was easy to understand, respectful, or produced any confusion or uncomfortable feelings)

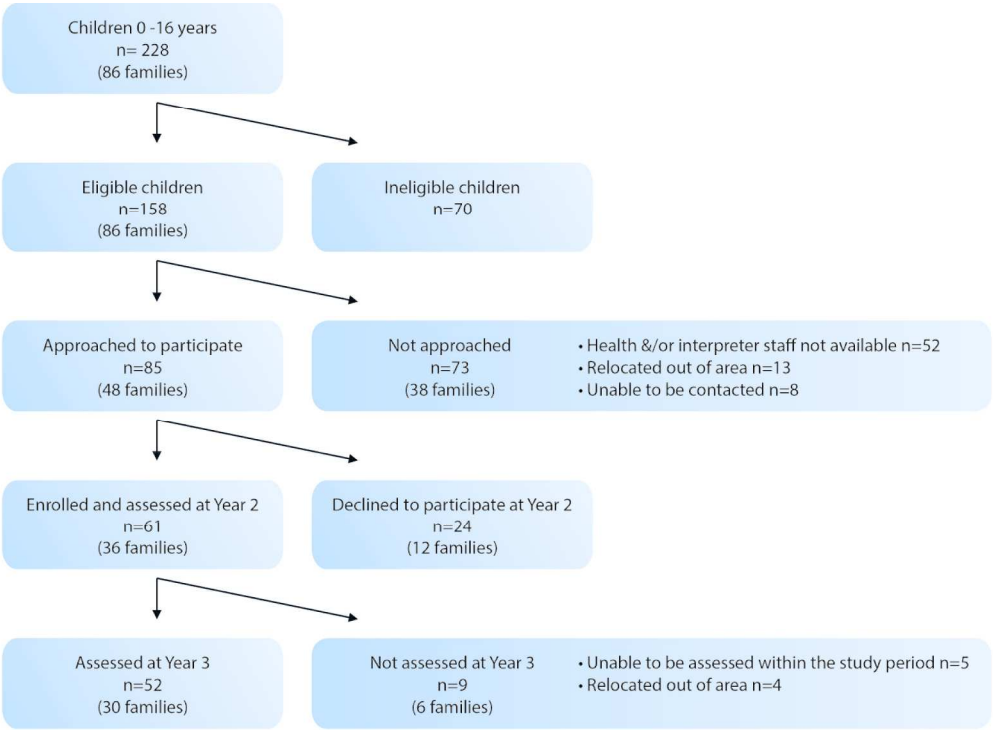

Figure 1: Recruitment and retention

232x169mm (300 x 300 DPI)

Research Checklist STROBE 2007 (v4) Statement for cohort studies

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) 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	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 periods of recruitment, exposure, follow-up, and data collection	6-7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	7
		(*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	9-12; Table 1 (pg 13) and Table 2 (pg 18)
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	12; Table 1 (pg 13) and Table 2 (pg 18)
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 variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	17-18
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	17-18
		(*b*) Describe any methods used to examine subgroups and interactions	n/a as this cohort study 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 numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	18; Figure 1

		(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 confounders	18-19; Table 3 (pg 20)
		(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	(*a*) 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	22-25
Limitations			23-25
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	25-26
Generalisability	21	Discuss the generalisability (external validity) of the study results	26
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	27

*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.