

CHAPTER 1

THE SURVEY – OBJECTIVES, DESIGN AND PROCESS

Summary.....	3
The Telethon Institute for Child Health Research.....	5
Survey objectives.....	5
Survey concept and development	6
Aboriginal direction.....	7
Community consultation and approval	7
Ethical approval for the survey	8
Indigenous identification and the scope of the survey	8
The survey population	8
Geographic distribution of the survey population.....	9
Questionnaire development.....	9
Pilot survey, dress rehearsal, and main survey	10
Non-response and refusal to participate	11
Survey outputs and community feedback	13
Research innovations	13
A new way of looking at remoteness and isolation	13
Record linkage between survey data and administrative data.....	17
Three level hierarchical modelling of weighted survey data.....	19
Survey significance	19





CHAPTER 1

THE SURVEY – OBJECTIVES, DESIGN AND PROCESS

The Western Australian Aboriginal Child Health Survey, a large-scale epidemiological survey of the health and well-being of 5,289 Western Australian Aboriginal and Torres Strait Islander children, was undertaken in 2001 and 2002 by the Telethon Institute for Child Health Research. The survey was designed to build an epidemiological knowledge base from which preventive strategies can be developed to promote and maintain healthy development and the social, emotional, academic, and vocational well-being of young people. This is the first undertaking to gather comprehensive health, psychosocial and educational information on a population-based random sample of Aboriginal and Torres Strait Islander children in their families and in their communities. This introduction broadly details the background and methods used to collect the data and also describe the survey sample.

SUMMARY

- The primary objective of the Western Australian Aboriginal Child Health Survey (WAACHS) was to identify the developmental and environmental factors that enable competency and resiliency in Aboriginal children and young people.
- Questionnaire content covered child and youth development, health and well-being, probes for functional impairment and disability, use and access to health, education and social services, and a selected number of questions about diet and nutrition.
- The survey was based on an area sample of dwellings. Families in selected dwellings who reported that there were, ‘Aboriginal or Torres Strait Islander children or teenagers living at this address who are aged between 0 and 18 years’, were eligible to be in the survey.
- An Aboriginal Steering Committee has directed the planning, implementation and reporting of the survey. The survey content and processes were developed in consultation with Aboriginal leaders, key Aboriginal bodies, and through extensive consultations throughout the state with Aboriginal community councils, parents and key service providers.
- The study methodology, data management and reporting processes met the requirements of the Western Australian Department of Health’s Aboriginal Health Information and Ethics Committee as well as the Ethics Committees of King Edward Memorial and Princess Margaret Hospitals.
- The Institute for Child Health Research (ICHR) is home to the Kulunga Network – a collaborative maternal and child health research, information and training network. The Kulunga Network is an advocate for Aboriginal children and families in Western Australia and is developing additional materials from the survey for Aboriginal readers.
- An index of Level of Relative Isolation (LORI) has been developed for use in this survey. LORI allows greater discrimination of the circumstances of survey respondents with respect to their isolation from population centres of various sizes and better differentiates between areas and communities that are extremely remote from major metropolitan centres.



- Over 95 per cent of interviewed carers gave consent for responses from this survey to be linked to their children's birth records and to their entries on the Hospital Morbidity Data System. This linkage to records of hospital admissions, diagnoses, procedures, and transfers adds power to the survey data by giving a comprehensive record of health services contacts.



THE TELETHON INSTITUTE FOR CHILD HEALTH RESEARCH

The Telethon Institute for Child Health Research is a centre of excellence for the conduct of research into child health. Founded in 1987, the Institute's research programs include the study of asthma and allergic disease, birth defects, child and adolescent mental health, childhood death and disability, leukaemia and other cancers as well as Aboriginal health and infectious disease.

The Institute's mission is to improve the health of children through the development and application of research into:

- causes of ill health
- the maintenance of good health
- prevention of ill health
- the treatment of conditions affecting children.

The Institute is the home of the Kulunga Network – a collaborative maternal and child health research, information and training network, involving the Institute for Child Health Research and member services of the Western Australian Aboriginal Community Controlled Health Organisation (WAACCHO). The Kulunga Network is an advocate for Aboriginal children and families in Western Australia. The Network seeks to ensure that community-based and culturally relevant research benefits them by influencing the policy and planning of government and other key agencies, and by involving Aboriginal people in all areas of research and implementation of outcomes. The survey was a project of the Network.

SURVEY OBJECTIVES

The survey's primary objective was to identify developmental and environmental factors that enable competency and resiliency in Aboriginal children and young people. There was emphasis on defining priority targets for existing and future health, education and social services. Building an epidemiological knowledge base from which preventive strategies can be developed to facilitate the social, emotional, academic and vocational competency of young people was a notable feature of this survey.

The specific aims of the survey were to:

- describe and define the health and well-being of Western Australian Aboriginal and Torres Strait Islander children and young people aged 0–17 years
- estimate the prevalence and distribution of commonly occurring chronic medical conditions and disabilities (e.g. asthma, cerebral palsy, visual and hearing impairments, intellectual disability) and describe how they may affect a child's well-being and functioning
- estimate the prevalence, distribution and functional impact of common health and mental health problems in Aboriginal children and young people aged 0–17 years and their families
- estimate the prevalence and distribution of adverse health behaviours (e.g. smoking, alcohol, drug and volatile substance misuse)



- estimate the prevalence and distribution of other psychosocial problems such as early school leaving, conduct problems, and juvenile offending
- describe Aboriginal and Torres Strait Islander children, adolescents and their families' access to, effective use of and satisfaction with health care, education, juvenile justice, housing and social services
- identify markers resulting in protection from, and amelioration of poor health and well-being (mental health), adverse health behaviour(s) and other psychosocial problems
- develop estimates of risk and markers identifying Aboriginal and Torres Strait Islander children and young people at increased risk for various health, educational and vocational outcomes.

SURVEY CONCEPT AND DEVELOPMENT

The concept of gathering child health and well-being information from families with Aboriginal and Torres Strait Islander children was first proposed in 1991 during the development of the Western Australian Child Health Survey^{1,2,3}. However, for reasons owing to scale, cost, and expertise, families with Aboriginal children were principally excluded from this earlier survey. The Telethon Institute for Child Health Research undertook to reassess the feasibility of conducting an Aboriginal Child Health Survey following the conclusion of the original Western Australian Child Health Survey. The assessment of the feasibility, design and scope of the Aboriginal Child Health Survey was subsequently undertaken between 1996 and 1999.

Survey methodology and instrumentation were developed in consultation with Aboriginal leaders, key Aboriginal bodies (the Aboriginal and Torres Strait Islander Commission regional council, the Aboriginal Council of Elders, the Aboriginal Justice Council, and WAACCHO), and through extensive community consultations throughout the state. A survey project team, reporting to an Aboriginal Steering Committee, had basic carriage of securing funding, developing the survey instruments, and implementing the fieldwork.

The Australian Bureau of Statistics was a principal provider of consultancy services, expertise and support through all phases of survey development, implementation and analyses. Efforts were made to ensure that the data collected are both scientifically relevant and pertinent to current government information needs and policy initiatives. To do this, reference groups were convened during 1997–1998 with representation from the various government departments and community agencies that had an interest in the outcome of the survey findings. This process involved senior policy input from the Western Australian State Departments of Health, Education and Training, Community Development and Police; the Alcohol and Drug Authority; the Disability Services Commission; the State Housing Commission; the Catholic Education Office of Western Australia; and the Association of Independent Schools of Western Australia. Commonwealth Departments were also consulted to advise on policy needs and were asked to specifically comment on content and design of the survey.



ABORIGINAL DIRECTION

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee. Established in 1997, the Steering Committee had the responsibility to control and maintain:

- cultural integrity of survey methods and processes
- employment opportunities for Aboriginal people
- data access issues and communication of the findings to the Aboriginal and general community
- appropriate and respectful relations within the study team, with participants and communities, with stakeholders and funding agencies and with the governments of the day.

COMMUNITY CONSULTATION AND APPROVAL

The survey represented a large undertaking involving extensive household sampling and voluntary participation in the survey of many Aboriginal and Torres Strait Islander people across Western Australia. Seeking support and approval for the survey required establishing an extensive and ongoing process of consultation. Repeated consultations were undertaken during 1998 and 1999 with specific visits to Aboriginal communities in Albany, Bunbury, Broome, Carnarvon, Collie, Derby, Esperance, Fitzroy Crossing, Geraldton, Halls Creek, Kalgoorlie, Karratha, Katanning, Kwinana, Kununurra, Narrogin, Perth, Pinjarra, Port Hedland, and Roebourne. Every attempt was made to engage participation of community leaders, community councils, administration staff, service providers, and local residents in discussing their views about the need for the survey and to request their approval to be included in the survey. People were asked about the methods and processes that they felt would assist or hinder the success of the survey, their requirements with respect to specific survey content, their expectations about the use of the survey data and intended outcomes.

The initial community consultations for the survey established that most participating carers and youth expressed a preference for the survey to be written and administered in plain Standard Australian English (SAE). The precise wording of survey questions was kept as simple as possible to accommodate a wide range of proficiency in SAE and Aboriginal English. The survey materials presented in this format were assessed in the pilot and dress rehearsal and found to yield reliable and valid information for all but the most remote and culturally intact Aboriginal communities where there was a high level of traditional language use. In these communities, the majority of (but not all) families chose to be interviewed with the assistance of an Aboriginal language translator employed through the local community council or Aboriginal Medical Service.

Approval for the survey was also obtained from WAACHO, the Western Australian Council of Elders, the Aboriginal Justice Advisory Committee and the Aboriginal and Torres Strait Islander Commission (ATSIC) State Council.



ETHICAL APPROVAL FOR THE SURVEY

This project met the requirements of, and was approved by, the Western Australian Department of Health's Aboriginal Health Information and Ethics Committee as well as the Ethics Committee of King Edward Memorial and Princess Margaret Hospitals. These clearances ensured that the survey process and procedures conformed with requirements and protocols for health research with Indigenous people and that they adhered to National Health and Medical Research Council (NHMRC) ethical standards and guidelines for research with human subjects.

INDIGENOUS IDENTIFICATION AND THE SCOPE OF THE SURVEY

The survey was based on area sample of dwellings (*see dwelling in Glossary*). Families in selected dwellings who reported that there were 'Aboriginal or Torres Strait Islander children or teenagers living at this address who are aged between 0 and 18 years' (*see Indigenous status in Glossary*) were eligible to be in the survey.

Children living within group homes, institutions and non-private dwellings were not in the scope of the survey. However, where a selected household had a child temporarily living away from home (e.g. in a boarding school or hostel), these children were included in the scope of the survey.

Once the authority for the survey and the nature of the survey was explained to a responsible adult (usually the carer(s) or head of the household), and consent to participate was obtained, Indigenous status was determined for each person who was reported to 'usually' live in the dwelling by asking, 'Does (the person) consider him/herself to be of Aboriginal or Torres Strait Islander origin?' Data were gathered on all Aboriginal and Torres Strait Islander children under the age of 18 in each of the participating households.

TERMINOLOGY

Throughout this publication the term 'Aboriginal and Torres Strait Islander peoples' has been used as the most precise and inclusive reference for Indigenous Australians. This is the form recommended by ATSIC for use in official documents. Where other group terms such as Aboriginal people(s), Australian Aboriginals and Indigenous Australians have been used, it should be noted that this is intended to refer to Aboriginal and Torres Strait Islander peoples.

THE SURVEY POPULATION

The terms 'children' and 'child' for this survey refer to persons under the age of 18 years at the time of the initial interview.

For purposes of analysis and presentation of the findings, they are further grouped into the following age groups:

- 0 to 3 years
- 4 to 11 years
- 12 to 17 years.



GEOGRAPHIC DISTRIBUTION OF THE SURVEY POPULATION

The impact of European settlement on Indigenous culture and ways of living has reflected the state's history of colonisation and how this has been shaped by the state's geography. Families with Aboriginal children live in an enormously diverse range of communities distributed across the state. Some of these communities are small and discrete and are located in remote and isolated areas and may have associated 'out stations' (*see Glossary*). Other communities may be within towns or on the outskirts or fringes of towns, while still others are part of rural centres or urban areas. Some of these communities, particularly those that are isolated from mainstream population centres, have predominately Indigenous residents. City areas on the other hand have proportionally small Indigenous populations scattered more widely across the urban areas.

Western Australia comprises over one third of the continental landmass of Australia. The northwest and centre of the state includes large tracts of desert and some of the most remote and sparsely populated areas in the world. The more populated southwest of the state includes extensive agricultural and forested areas with numerous small population centres. Over two thirds of the State's total population and one third of the Aboriginal and Torres Strait Islander population resides in the metropolitan area of Perth. Physical distance is not the only form of isolation for Aboriginal people. Psychological, social, spiritual and cultural isolation or distance within society can also impact on health and well-being. Some may argue that this may be greater in larger metropolitan centres due to the relative minority status in the population and hence a greater potential to experience alienation from mainstream society.

QUESTIONNAIRE DEVELOPMENT

The survey was designed to place as low a burden on respondents as possible while at the same time acknowledged that sufficient time must be spent in gaining access, understanding and a good level of rapport with respondents. The interviews took considerable time, and multiple visits were often necessary to ensure complete data and to minimise respondent fatigue. Interviews were budgeted for a three-hour time period per household in which no more than 90 minutes would be used in formal data collection.

Questionnaire content covered child and youth development; health and well-being; functional impairment and disability; use and access to health, education and social services; and a selected number of questions about diet. These data were collected from interviews with the carers in the household who were the most knowledgeable about the survey children. In addition to the information collected on children, separate interviews were undertaken with up to two carers per child to gather information about the demographic and social characteristics of the household and family and to ask questions about the dwelling, neighbourhood and community. Consent was obtained from carers and young people to collect separate health and well-being information from young people aged 12–17 years.

Where possible, processes and measures paralleled those used in the study of mental health in the 1993 WA Child Health Survey. Many of the data items were selected from previous surveys of Indigenous families and communities while other items were specifically developed and piloted for this survey.

Throughout 1998 and 1999, repeated visits were made to remote and rural Aboriginal communities to consult with Aboriginal stakeholders and potential participants. Meetings and focus groups were used to determine content of the



survey questionnaires. Specific interests and needs were identified. Of particular interest to Aboriginal people and communities were the following:

- alcohol use and problems
- gambling – particularly where this involved children
- difficulties getting enough sleep
- violence in communities and families
- how children are doing at school
- aspirations of young people and their hopes for the future
- experiences of racism
- use of Aboriginal language(s)
- diet and nutrition.

In 1999 and 2000, the pilot and dress rehearsal phases were used to refine the questionnaires. In the main, questions were culled where they were shown to be ineffective or of low meaning and relevance. The order and sequence of the questions was subject to considerable revision to make the questionnaire content logically flow and tell a more appropriate story.

A guide to the survey fieldwork instruments is presented in Appendix A.

PILOT SURVEY

Prior to the dress rehearsal and main survey, a pilot survey was carried out in September and October 1999 in Kununurra, Beagle Bay, Kalgoorlie, Northam, Lockridge, and Bentley. Seven experienced interviewers approached 55 Indigenous households seeking consent for participation in interviews. A total of 51 households consented (93%). Information was gathered on 95 children aged 0–17 years. This pilot tested all aspects of the questionnaire design, community acceptability, burden on both the participating families and the interviewer, and assessed sample and data yield. A full debriefing with the interviewers took place in October 1999. Data quality and the survey processes were agreed to be acceptable. Extensive modifications were undertaken to the design of the survey forms to improve administration of the interviews. Additionally, content and item wording were modified where this was needed to improve face validity and where empirical analysis and interviewer feedback indicated improvements could be made.

DRESS REHEARSAL

Following a revision based on the pilot, a full dress rehearsal was undertaken in April 2000. The aims of the dress rehearsal were to formally test the training curriculum for use with Indigenous and non-Indigenous interviewers; test the field procedures; and assess the final survey content, process and yield. This involved recruiting and training eight screeners who listed the dwellings in the census districts, screened households and approached eligible families in urban and town areas, and training nine interviewers who conducted the interviews in Kwinana, Gosnells, Carnarvon, Geraldton, Collie, Halls Creek, Port Hedland, Pinjarra and Stirling. In all, 95 families with 225 children were randomly selected and interviewed.



MAIN SURVEY

The main survey commenced in May 2000 and was completed in June 2002. Dwellings were selected for screening using an area-based clustered multi-stage sample design. From 166,290 dwellings in 761 census collection districts, 139,000 dwellings were approached to determine if residents were eligible to participate in the survey. Using this method, a random sample of 2,386 families with 6,209 eligible children was identified throughout metropolitan, rural and remote regions of Western Australia. A total of 1,999 of these families (84 per cent) with 5,513 eligible children consented to participate in the survey. Interviewers gathered useable data on 5,289 (96 per cent) of these participating children. In addition to the data gathered on children, data were also gathered on families from:

- 2,113 (95 per cent) participating carers identified as the persons who knew the most about the individual survey child (*See primary carer in Glossary*)
- 1,040 (83 per cent) other participating carers of the survey children (*See secondary carer in Glossary*) wherever this was possible and wherever they were present in the household
- 1,073 (73 per cent) participating young people aged 12 to 17
- the school principal and teacher(s) of surveyed children in 388 Western Australian schools.

TERMINOLOGY

Throughout this publication the terms ‘primary carer’ and ‘secondary carer’ have been used to describe those adults nominated to provide information about children selected in the survey. Primary and secondary carers were considered to be the people who spent the most time with the children and who knew them best. In most cases, the primary carer was the mother of the child.

From October 2000, the 3,419 survey children who were in school were followed up with survey instruments that collected details from the school principal and the classroom teacher. A total of 485 schools were sent survey materials and returns were received for about 2,379 (70 per cent) children attending approximately 388 of these schools. This allowed estimates of health, mental health and competencies as observed in the school context. Information was also gathered from school principals about the school’s physical, social and community environment and about the capacity of the school to meet its educational mission.

NON-RESPONSE AND REFUSAL TO PARTICIPATE

Non-response characteristics. For families that participated in the survey, information on the primary carer and on children as reported by the primary carer was almost always obtained (95 per cent and 96 per cent respectively). However where separate contact was required with other household members (i.e. the secondary carer or youths), the response rate was considerably lower (83 per cent and 73 per cent respectively).

Non-response at the family and person level was dealt with by means of weighting adjustments. These adjustments were derived after comparing the distribution of a range of characteristics for the survey respondents with data from the 2001 census. Characteristics chosen included sex, region, age, ability to speak an Aboriginal language, school attendance, carer education, carer income, household size, dwelling type, dwelling ownership and tenancy arrangements.



Of the characteristics considered, significant differences were found between sample and population distributions according to child's age, and number of persons living in the household. From age 12 years to age 17 years there is a continuing decline in representation of older children such that by age 17 years, participation in the survey was 40 per cent lower than expected based on census figures. The survey also had a lower proportional representation of children living in small households. These characteristics were also found to be associated with survey participation in the 1993 WA Child Health Survey. None of the other characteristics tested were found to be associated with response rate.

Finally, additional information was collected about young people using a youth self-report form. The interviewer could either administer the form, or it could be left with the youth for self-completion and later collection. Only 73 per cent of youths in participating families completed the youth self-report. For many of the non-responding youths, information was available from the primary carer. This made it possible to compare characteristics of respondents and non-respondents to the youth form by using information collected from the primary carer.

Youths responding to the youth self-report were more likely to be aged between 13–15 years and to be living in the Perth metropolitan region, while non-respondents were more likely to live in CDs classified to the bottom 5 per cent of socio-economic disadvantage, to have had contact with police, juvenile justice or courts, or have an abnormal mental health problem score.

These results suggest that youths with significant mental health and behavioural problems are under-represented in the respondents to the youth self-report. While the weights have been designed to compensate for the differential response rates by age and region, it is not possible to adjust for the lower representation of youths with mental health problems, as no population benchmarks are available at this level.

CHARACTERISTICS OF FAMILIES WHO REFUSED TO PARTICIPATE

In addition to examining characteristics of respondents compared to census distributions, some rudimentary information was collected about the 387 families who refused participation in the survey. At the time of initial screening, the interviewer explained the importance of having some information on families that were not able or willing to participate. As a result, a Household Record Form was completed for 245 of these families. This provided a list of all the residents of the household, their ages, Indigenous status and relationships within the household. Of the remaining 142 dwellings where the family refused to participate, the interviewer was able to obtain a basic age breakdown of the number of in-scope children living in the household in 92 cases. In the remaining 50 dwellings, families refused to give any indication of the number of in-scope children resident.

Analyses showed that families with older children were more likely to refuse participation. In the Perth region, household size and socio-economic status were also significant predictors, with families refusing to participate more likely to live in large households and live in more disadvantaged areas. Within the South West and the Midwest and Goldfields regions, the only significant association was with older age of child. In the Kimberley and Pilbara, household size was also a significant factor with non-respondents more likely to come from large families.

Because of these findings, age, region and household size are factors that have been incorporated into the weighting design.

Further information about non-response and sample weighting may be found in Appendix B.



SURVEY OUTPUTS AND COMMUNITY FEEDBACK

Four further volumes of results from the Western Australian Aboriginal Child Health Survey are planned. Forthcoming volumes will focus on Social and Emotional Well-being, Education, Family & Community and Justice issues. A Summary booklet for each volume will be produced. As well there are plans to write a number of research papers and professional journal articles.

A communication and dissemination strategy has also been designed to maximise knowledge and awareness of the findings to both the Aboriginal and wider communities. The strategy, to be driven by the Kulunga Research Network, aims to engage Aboriginal communities in committed action, using the data as a catalyst for political and community action and social change. The data results and findings will be reported and profiled for each of the ATSI regions throughout the state.⁴

A pilot study has been conducted in the Fitzroy Valley region of the Kimberley to initialise the first key steps of the communication and dissemination strategy. The steps of this study involved consultation with communities to determine preferred methods for feedback of findings, requirements for region-specific information, and communities' overall survey experience. Feedback from the pilot showed that community members were positive about receiving feedback, that they preferred plain language information materials with a strong focus on visuals, and that all participants should be included in the feedback process. These understandings will guide the production of community information resources and point toward the conduct of an extensive series of meetings workshops and seminars.

RESEARCH INNOVATIONS

To maximise the usefulness of the data from this survey, a number of innovative research tools and methods were developed or used. These include:

- a new way of looking at remoteness and isolation
- record linkage between survey data and administrative data and
- three level hierarchical modelling of weighted survey data.

A NEW WAY OF LOOKING AT REMOTENESS AND ISOLATION

The Accessibility/Remoteness Index of Australia (ARIA) is the commonly used standard classification of remoteness and access to services. Produced by the National Key Centre for Social Applications of Geographic Information Systems (GISCA) in 1997 for the Commonwealth Department of Health and Aged Care, it has been rapidly adopted throughout the country. The ABS has included a refined version of the ARIA, called the ARIA+, in the Australian Standard Geographic Classification for the 2001 census.

ARIA is based on scoring the distance from every locality in Australia to service centres of varying sizes. The ARIA score, ranging from 0 to 12, puts locations on a gradient from large capital cities through to very remote regions. It has worked well in describing the total population of Australia. However in our first analyses of WAACHS data, it became apparent that it masked considerable variation in the remoteness and access to services of Aboriginal communities. For instance, while only 1 per cent of the total population of WA lives in areas classified as very remote under ARIA and ARIA+, over 25 per cent of Aboriginal and Torres Strait Islander people in the state live in these very remote areas which comprise over two-thirds

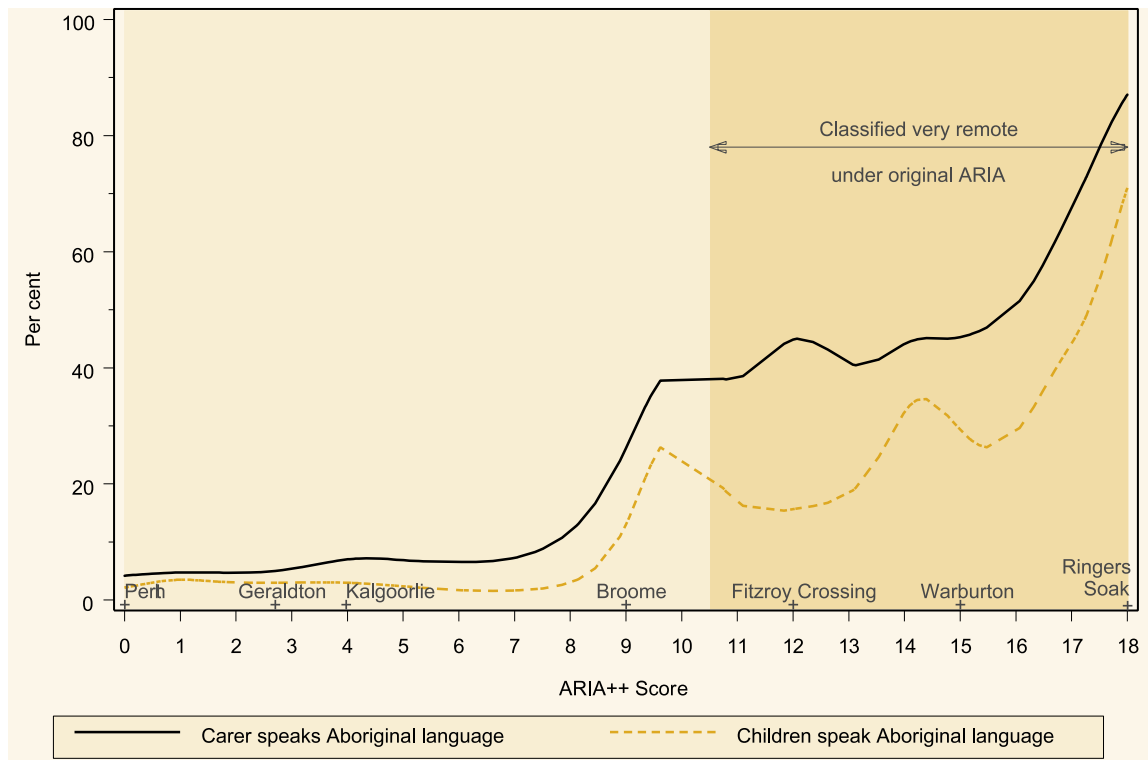


of the land mass of the state. The WAACHS data showed that there were large variations in the circumstances of Aboriginal communities within this region ranging from small regional centres like Fitzroy Crossing with its own hospital servicing the surrounding region, through to truly isolated Aboriginal communities with strong ties to traditional cultures and lifestyles.

GISCA has recently produced a further product, ARIA++, which extends the range of service centres used in scoring the index by adding a further category for centres with a population of 200–999. The ARIA++, which scores on a range from 0 to 18, has been used in our analysis of WAACHS data. The extra discrimination at the remote end of the scale has been very effective in discriminating between communities with quite different characteristics within very remote Australia.

As one example, Figure 1.1 shows the proportion of carers and children who speak Aboriginal languages by ARIA++ score. Locations scored above 10.5 (defining Very Remote in the original ARIA) range from 40 per cent of carers speaking an Aboriginal language to almost 90 per cent. This variation is masked under ARIA by treating these diverse regions as equally remote.

FIGURE 1.1: PROPORTION OF CARERS AND CHILDREN WHO SPEAK ABORIGINAL LANGUAGES, BY ARIA++



To simplify analysis, 5 levels of remoteness have been created for the WAACHS based on the new ARIA++ score from GISCA. The cut-off scores for these regions were determined from an analysis of WAACHS data which identified cut-off points that produced regions that are as internally homogenous as possible, while conveying the differences across the continuum of remoteness.

To avoid confusion with the existing ARIA and ARIA+ classifications and the ABS adoption of ARIA+, new language has been chosen to describe these ARIA++ levels. In this publication the five levels are referred to as Levels of Relative Isolation (LORI) and have been labelled None, Low, Moderate, High and Extreme. The first level, LORI None, corresponds exactly with Capital City Australia under ARIA+. In WA, this is the Perth Metropolitan area. Each of the other four regions has been constructed specifically for WAACHS, and differs from the regions defined under ARIA or ARIA+. Figure 1.2 shows the distribution of survey children in these five regions.

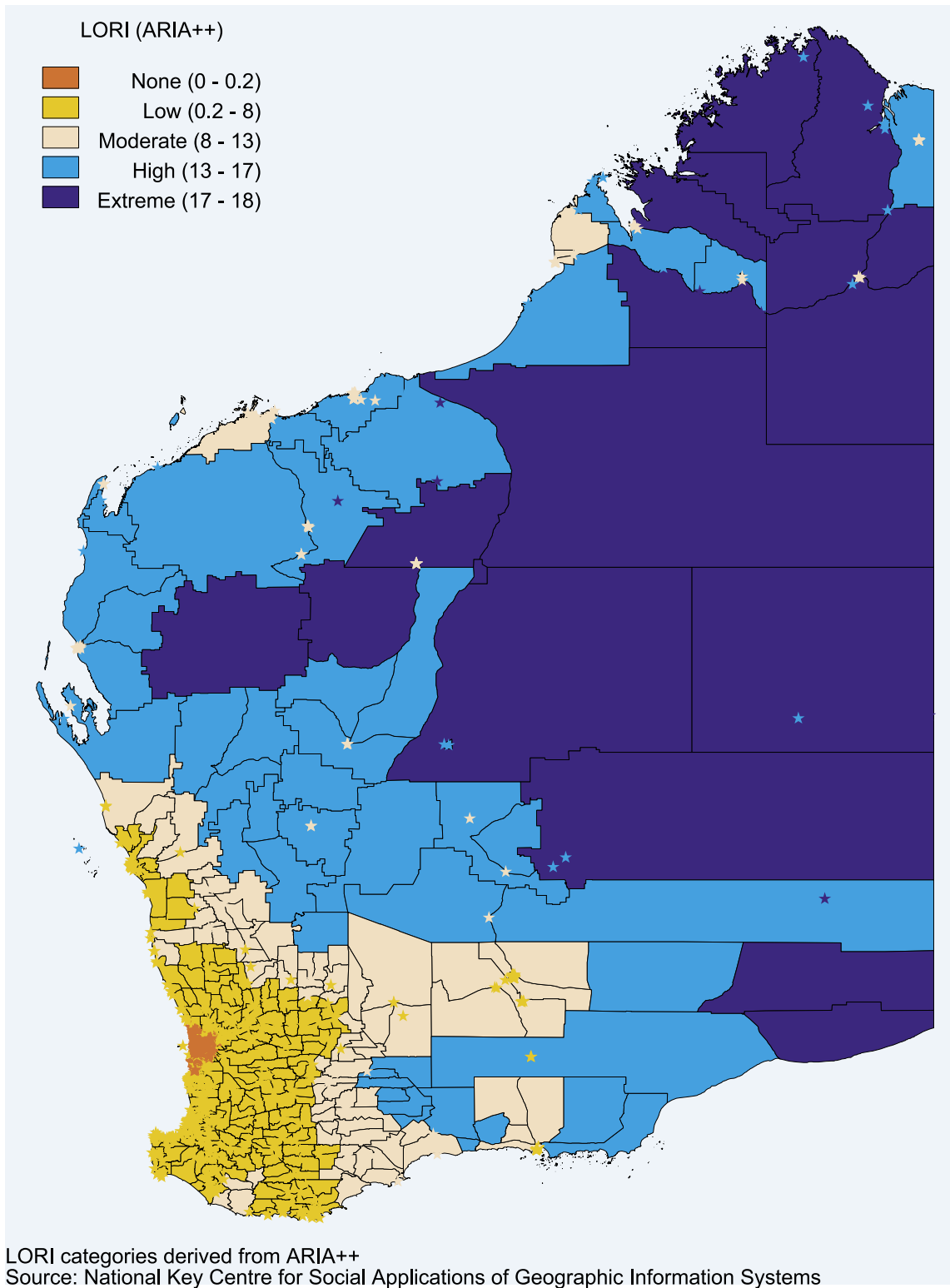
FIGURE 1.2: LEVEL OF RELATIVE ISOLATION (LORI) CATEGORIES: ARIA++ RANGES

Level of relative isolation	ARIA++ range	Proportion of WAACHS children %
None (Perth Metropolitan area)	0 – 0.2	30.9
Low	0.2 – 8	31.7
Moderate	8 – 13	18.3
High	13 – 17	9.8
Extreme	17 – 18	9.1

Figure 1.3 maps the five LORI regions in WA. Locations such as Halls Creek and Fitzroy Crossing are classified as moderate relative isolation. Warburton has high relative isolation while the surrounding central desert communities have extreme relative isolation. Under ARIA and ARIA+ all of these locations are classified as 'Very Remote'. For details of ARIA++ and the derivation of the LORI categories, see Appendix C.



FIGURE 1.3: WA CENSUS COLLECTION DISTRICTS – LEVEL OF RELATIVE ISOLATION (LORI) CATEGORIES BASED ON ARIA++ VALUES

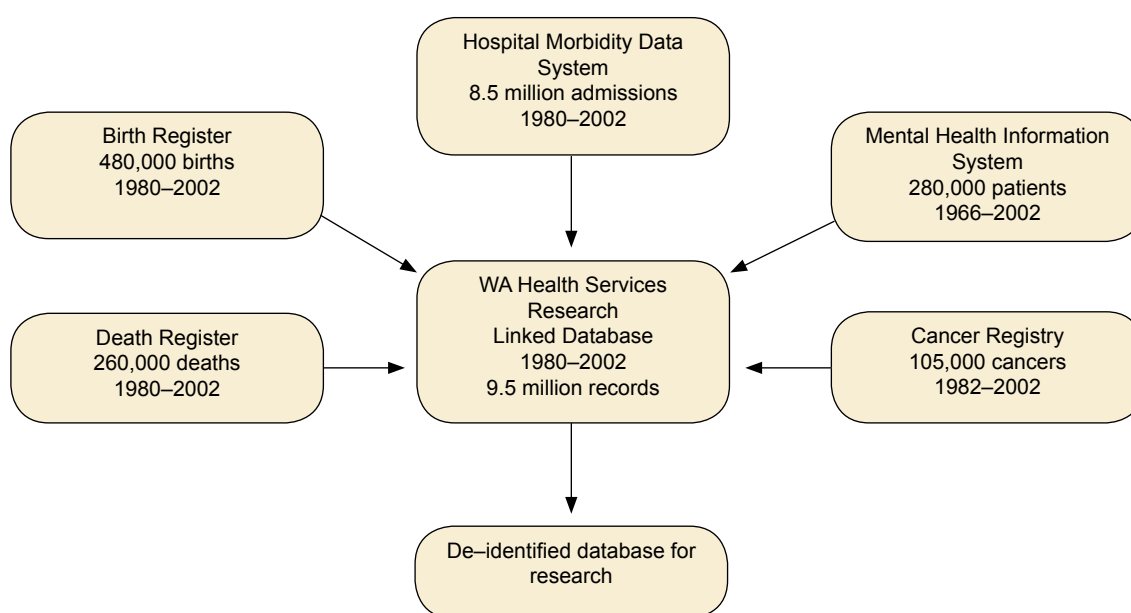


RECORD LINKAGE BETWEEN SURVEY DATA AND ADMINISTRATIVE DATA

Carers were asked for consent to access their hospital records, as well as the birth and hospital records of their children. Carers who consented were given the opportunity to opt out at any stage should they change their mind. The vast majority of carers consented to these records being accessed. Of primary carers, 96.7 per cent consented to allow access to their hospital records, while 92.8 per cent of secondary carers gave similar consent. Overall, 96.3 per cent of all carers gave consent for their children's birth and hospital records to be accessed.

The WA Record Linkage System

The WA Record Linkage System is unique in Australia, and one of only a handful of similar data collections in the world. It links together birth and death registrations with administrative hospital data from several sources to give a comprehensive record of health services contacts for the population of Western Australia. Figure 1.4 shows the major components of the WA Record Linkage System. As there are no unique identifying numbers, probabilistic record linkage has been used to link the files together. This operates on matching names, dates of birth, hospital names and addresses. The procedure allows for possible changes in the matching fields by calculating the probabilities of records being correct matches. Records that are potential links are clerically reviewed, and overall the error rate is less than 1%.⁵

FIGURE 1.4 THE WA RECORD LINKAGE SYSTEM

Key components of the record linkage system for use with the WAACHS are the birth records and the Hospital Morbidity Data. The birth registrations have been combined with data from forms filled in by midwives to produce the Maternal and Child Health Research Data Base (MCHRDB)⁶. For every midwife-attended birth in Western Australia wherever it occurs, the midwife submits a completed form indicating the characteristics of the infant, its condition at birth, details of the pregnancy and delivery together with some demographic details.

The Hospital Morbidity Data System (HMDS) records every admission to private and public hospitals in WA since 1980. The system records demographic information about the patients, diagnostic information (coded using the 9th and 10th revisions of the International Classification of Diseases)^{7,8} and information about service use including length of stay, any procedures performed in hospital, and transfers between hospitals.

While almost all carers gave consent for record linkage to occur, it was not always possible to match records. Approximately 5 per cent of survey children were born outside of WA and thus could not be linked to their birth records. Overall, 4,637 of the 5,289 survey children were successfully linked to their birth records (87.7 per cent).

While several key components of the WA Record Linkage System date back to 1980 or earlier, the oldest survey children were born in 1982. Where population comparisons have been derived from the full set of linked data for the total population, the period 1982–2001 has been used as the relevant reference period.

Community Housing and Infrastructure Needs Survey

The Community Housing and Infrastructure Needs Survey (CHINS) was conducted in 1999 and 2001 by the Australian Bureau of Statistics on behalf of ATSIIC. ATSIIC kindly provided a copy of the 2001 CHINS data which has been linked to WAACHS data by community. Some 1,089 of the 5,289 survey children (20.6 per cent) were living in discrete Aboriginal communities covered by the CHINS. CHINS collects a large range of information about services in Aboriginal communities in addition to information about the quality of community infrastructure and housing stock. Access to the CHINS data for discrete Aboriginal communities will allow the examination of the relationship between a range of community characteristics and child health and well-being.

The use of record linkage adds considerable value to the survey data, without burdening respondents with extra questions. It enables the study of children's current health and well-being in the light of prior encounters with the health system and their health status at birth, including detailed diagnostic information that carers could not be expected to know.



THREE LEVEL HIERARCHICAL MODELLING OF WEIGHTED SURVEY DATA; CHILDREN, CHILDREN IN FAMILIES, CHILDREN IN COMMUNITIES

The nature of the survey data presented several challenges for statistically appropriate analysis. Unlike data collected from a simple random sample, the survey children are clustered within families and communities. The sample was selected in three stages: census collection districts (CDs), families and children. CDs were selected with probabilities of inclusion in the survey proportional to the number of Aboriginal and Torres Strait Islander children living in the CD. Once families had been selected, each Aboriginal and Torres Strait Islander child under the age of 18 years was selected in the survey. As a result of this selection hierarchy, the data for individual children in the survey sample violate one of the basic assumptions of traditional regression modelling: that the observations are independent. For many data items, children within the same family are more likely to have the same characteristics than children chosen randomly from throughout the state.

Multi-level, or hierarchical, modelling can be used to account for the hierarchical structure of the survey data.⁹ The analysis is further complicated because unequal probabilities of selection have been used. CDs have been selected into the sample with probabilities proportional to the number of in-scope children. Survey weights have also been developed to adjust for different levels of non-response by age group and family size. While there are techniques to model data collected from surveys where unequal weights are used, and a range of software available that can fit multi-level models, addressing both issues at the same time is a relatively new statistical challenge. Pfeiffermann *et al*¹⁰ proposed a technique, called Probability Weighted Iterative Generalised Least Squares (PWIGLS) that can fit a multilevel model accounting for a complex survey design. The PWIGLS technique as described by Pfeiffermann *et al* fits a two-level model to a normally distributed continuous variable. We have adapted this technique for the WAACHS where we wanted to model a three level hierarchy: children within families within communities. As many of the survey variables are binary indicators we have also adapted the PWIGLS technique to fit logistic regression models (*see Glossary*). These new techniques have been implemented within SAS software. As far as we know, this is the first time such techniques have been used in a full-scale survey.

Where modelling results are shown in this volume, the models have been fitted accounting for both the hierarchical structure of the data, and the survey design and survey weights. Multi-level models are an ideal analytic tool for use in the survey, as they enable children's health and well-being to be described in terms of not only child level factors, but family and community level factors as well. The use of survey weights allows us to generalise the results of the models to the entire population of Aboriginal children in Western Australia.

SURVEY SIGNIFICANCE

This is the first undertaking to gather comprehensive health, psychosocial and educational information on a population-based random sample of Aboriginal and Torres Strait Islander children in their families in their communities. The extent of the sample, complexity of the sampling strategy, logistics and demands of the field work, and endeavours to engage Aboriginal leadership and input into the design of the field methods and questionnaires, make this project one of considerable social and scientific significance. The active involvement of State and Commonwealth agencies, and obligation on the part of the survey team to provide meaningful and relevant information and feedback to Aboriginal communities should ensure that important policy needs are addressed and information critical to assist planning, prevention and intervention is made available.



ENDNOTES

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