



**Report on the suggested expansion of the
Australian Longitudinal Study on Women's
Health to include additional Indigenous women
living in urban areas.**

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Summary

This report was commissioned by the Commonwealth Department of Health and Ageing to examine the feasibility of expanding the Australian Longitudinal Study on Women's Health (ALSWH) by recruiting additional urban Aboriginal women and Torres Strait Islander women. The purpose of such an expansion would be to provide adequate data for health service policy makers, planners and providers and for public health research into matters relating to the health of Indigenous women.

There are two main sections to the report. One discusses ethical issues and the principles of Indigenous research. The other examines a range of methodological issues specific to expanding the ALSWH and increasing its capability to provide valid and reliable information relating to the health of Indigenous women.

Established and emerging principles of ethical research involving Indigenous people go beyond the current NHMRC Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (1991). Consultation is a foundation stone. A national study would require particularly complex consultations with numerous communities and organisations, not only at the design stage but throughout the life of the project. The principle of benefit to Indigenous peoples from research includes interventions to improve health as well as enhancing research skills in the community and sharing the rewards of research. Community involvement includes acceptance of Indigenous ways of knowing, culturally appropriate methodology, ownership of data, and authority regarding the dissemination of findings.

There are considerable methodological challenges in conducting longitudinal studies involving Indigenous people. These were recognised in the initial submissions for the ALSWH. Subsequent experience, including separation of the main ALSWH and the Indigenous component, the Aboriginal and Torres Strait Islander Women's Health Project, has elucidated the issues. Indigenous women die younger and their life stages are compressed relative to other Australian women. A life course perspective therefore requires a different time frame as well as needing to take account of Indigenous issues of identity, community, land and self-determination. It is frequently argued that for Indigenous research, the community rather than the individual should be the unit of analysis. At an individual level, the notion of continual participation in a project over time with following and keeping track of people is likely to be treated

with suspicion and this is can result in poor recruitment and retention rates. Nevertheless, despite these limitations several longitudinal research projects involving Indigenous people have been (or are being) conducted. The lessons that can be learnt from them include the crucial role of consultation and on-going communication, the need for long and flexible time frames, and demonstration of clear benefit to the communities involved

Lack of good quality Indigenous identifiers in major national databases (including Medicare and electoral rolls) means that it is difficult to obtain a sampling frame of a study of Indigenous health from a population perspective. Additionally some features of the ALSWH, such as the use of mailed, written questionnaires, are likely to be particularly problematic. Also, the validity of some of the scales may be sensitive to cultural differences.

As the ALSWH is already established and the main methodology has been in operation since 1996, the fundamental consultation needed before the commencement of any study of Indigenous health is not possible. For this reason alone we strongly recommend against trying to recruit additional Indigenous women from urban areas to the study. Furthermore many of the methods used in the ALSWH are inappropriate for examining Indigenous health and any findings will be of dubious value.

Chapter 1: Introduction

This report was commissioned by the Commonwealth Department of Health and Ageing to examine the feasibility of expanding the current Australian Longitudinal Study of Women's Health (ALSWH) by recruiting additional urban Aboriginal women and Torres Strait Islander women into the study. The purpose would be to provide adequate data for health service policy makers, planners and providers and for public health research into matters relating to the health of Indigenous women.

The ALSWH is a nationwide study that has followed women in three age cohorts since 1996. The broad aim of the ALSWH is to investigate biopsychosocial factors that influence health and the use of health services across the life course. The research was designed to follow women through life events that have been considered critical to health, including movement into the workforce, establishment of adult relationships, motherhood, menopause and widowhood (Lee, 2001). The study has been designed to inform policy by exploring the broad areas of health service use, health-related behaviours, time use, life stages, and violence and abuse. Women were randomly sampled from the Medicare database with women in rural and remote areas sampled at twice the rate of urban women. Of the 41,606 women who consented to participate in 1996, 430 (1.03%) identified as Aboriginal or Torres Strait Islanders, 296 in the young cohort, 134 in the mid-age cohort and none in the older cohort. Between Surveys 1 and 2, the retention rate for Indigenous women was 48% and 74% for young and mid cohorts respectively, compared to 68% and 91% for non-Indigenous participants.

At the outset of the study it was recognised that the sampling frame of the ALSWH would inadequately access certain groups of Australian women including women from non-English speaking backgrounds and Aboriginal and Torres Strait Islander women. It was also apparent that specific concerns of these groups would not be address within the main study of the ALSWH and "Special Cohorts" were established to address these issues. At this time the main study was contracted to the University of Newcastle, with the Special Cohorts, including the Aboriginal and Torres Strait Islander Women's Health Project, subcontracted to the University of

Queensland. Difficulties with the contracting arrangements resulted in a separation of the contracts in 2001. The Aboriginal And Torres Strait Islander Women's Health Project operates with a different study design and methodology to the main study and has to date collected data from approximately 490 women.

It is estimated that an expansion of the ALSWH would require an addition of approximately 3000 women in each age cohort to be investigated. Allowing for a drop-out rate similar to that seen for Indigenous women in the main study this would leave a cohort of approximately 1000 women in ten years time and allow the study to detect effects of around 3% or more. As this report will outline, such a study would represent an enormous undertaking and far exceed any longitudinal research undertaken in Indigenous health to date.

The first chapter of the report discusses principles of Indigenous research and outlines the ethical issues that would arise from the suggested expansion of the ALSWH. This includes comment on the complex procedure for obtaining ethical approval in a national study and addresses the fundamental concerns of consultation, community involvement and ownership and publication of data as they relate to this proposal.

The second chapter addresses the methodological and practical considerations for expanding the ALSWH cohort. It debates the appropriateness of a longitudinal study of Indigenous women and discusses issues of sampling, confidentiality, survey content and mode of administration.

The report concludes with recommendations regarding the suggested expansion of the ALSWH and a discussion of future considerations regarding the relationship between researchers, research communities and government bodies involved in Indigenous health research.

Chapter 2: Principles of Indigenous research

Introduction

There is a growing body of literature that examines the principles of conducting research with Indigenous peoples (Paul and Atkinson, 1999; Smith 1999). Both in Australia and abroad it has been acknowledged that Indigenous communities at best have been over-researched and under-compensated; at worst, they have been exploited, stigmatised, disrespected and misrepresented as a result of their involvement in research (Humphery, 2000; Rigney, 1997). These criticisms have been levelled at a range of disciplines including public health. For these reasons, it is appropriate to reflect on the principles of research with Indigenous peoples and examine specific ethical issues that relate to Aboriginal and Torres Strait Islander health research.

The following discussion begins with an introduction to the concerns of Indigenous people throughout the world as they relate to research, and directs the reader to key publications in this area. It is evident that the trend towards increased community participation and ownership of research by Aboriginal and by Torres Strait Islander communities reflects a worldwide movement of Indigenous people asserting their right to full and active participation in all research issues that concern them. Following this is a brief outline of some of the primary complaints that Aboriginal groups and Torres Strait Islander groups have voiced about the past conduct of researchers who have entered their communities. While it is not appropriate to discuss these issues in depth here, it is important to recognise that the current debate around ethics in Indigenous research is grounded in an historical context. In this way the formal ethical guidelines can be seen against the history of poor relations with researchers and can be understood to encompass principles of respect and empowerment that are beyond a narrow interpretation of the ethical guidelines themselves.

The suggested expansion of the ALSWH to include a cohort of urban Indigenous women would need to meet the NH&MRC's Guidelines on the Ethical Matters in Aboriginal and Torres Strait Islander Health Research (1991). Further, a nationwide project such as the ALSWH would need to consider the ethical guidelines and research protocols that have been established by some States and by local communities to oversee Indigenous research. The requirements of these organizations are discussed briefly in addition to NH&MRC guidelines to highlight the complexities of negotiating ethical clearance in a nationwide study.

The recent emphasis on ethical guidelines has in some ways distracted from the issue of reflecting on the process of research itself and the establishment of alternative ways of knowing and investigating in an Indigenous health context. The ethical conduct of research must encompass more than issues of consent and consultation. The very nature of research must be questioned; traditional methodologies are under scrutiny by Indigenous communities who are critiquing Western research techniques and their applicability in an Indigenous setting.

Any research with Indigenous groups should begin from a point of negotiation, wherein the community leads the researchers and the funding bodies in establishing what it is that the community wants or needs to know about its people and their health. At all times the principle of benefit must be at the forefront: what information will benefit this community, what do people need to know in order to achieve better health? This shift from investigator-driven to community-driven research is one which at present remains problematic for funding bodies but which nonetheless is essential if Indigenous communities are to realise the goal of self-determination and control of research.

This chapter draws on the literature of Indigenous research methodologies, ethical principles of research, and the experience of researchers working with Indigenous communities. The text is interspersed with quotations from Indigenous scholars and commentators whose voice should be at the forefront of any debate on Indigenous research. It is their work and the work of others in the Aboriginal Health field that warrants further attention from both researchers and funding bodies if Australia is to move towards research conduct which supports self-determination of the Aboriginal and Torres Strait Islander peoples.

International Perspectives on Research Involving Indigenous Peoples

It is a complaint common to many Indigenous peoples around the world is that they are frequent targets of research yet rarely the recipients of benefits that this knowledge brings. Historically the relationship between Indigenous peoples and researchers has been a difficult one. Norton and Mason (1996) have commented on the numerous conflicts between American Indian and Alaskan Native tribes and those involved in their research. They suggest that the lack of respect shown to communities and the tendency to publish and profit from sensitive cultural information contributed to the strained relationships that are still evident today. Others point to research content and note that much of the work carried out in Indigenous communities has failed to address local priorities (Achanfuo-Yeboah, 1995). Stout and Kipling (1998; 9) discuss the history of Aboriginal women's health in Canada and conclude that much of the past research has focussed on issue of "questionable significance ...to women in the course of their daily life". In response, Indigenous groups are increasingly setting their own research priorities to ensure that they are the ones asking the questions and that the results of research address issues relevant to their communities. Smith (1999) takes this argument further, noting that it is also the way research is framed and the methodologies employed that have created tensions. The application of methods that are culturally inappropriate has produced data of questionable validity and reliability and led to research outcomes that lack meaning in a local context. Smith has been supported by her Australian peers in a call for new approaches in Indigenous research and recognition of alternative ways of "investigating" and "knowing" (Holmes et al., 2002; Langton 1994; Rowse 1996). Apparent in the discourse surrounding these issues is the sense that Indigenous knowledge and Indigenous research have an integral role to play in self-determination. An awareness of these more global issues is required to understand the challenges of undertaking research in Aboriginal communities and to fully appreciate the principles of Indigenous research.

Historical Context

Since the late 1970s and early 1980s authors such as Liddle and Shaw (1983) have been advocating 'reform' in Indigenous research. Humphery (2000) describes how Liddle and Shaw outlined six key areas for these reforms: Aboriginal control of and participation in research, research governed by Aboriginal-identified priorities, use of culturally sensitive methods, supervision of research by Aboriginal organisations, pursuit of research which brings benefit to the participating communities, and Aboriginal ownership of data and control of dissemination of results. At this time, Aboriginal organisations and Indigenous and non-Indigenous scholars began articulating strong concerns regarding the conduct of research with Aboriginal communities and the outcome of these endeavours (see, for example, Briscoe, 1978, and Brady, 1981). They discussed the practice of postgraduate students in particular, who collected data in communities without their knowledge or consent. They voiced disgust at the absence of compensation or recognition of the contribution of Indigenous knowledge to research and they documented some of the most negative (if unintended) consequences of research and the mainstream media's interpretation of research results. The litany of complaints about research led organisations such as Central Australia Aboriginal Congress (CAAC) and others to draft formal guidelines for health research in an effort to protect Indigenous participants from exploitative and harmful research practices and to alert non-Indigenous researchers to the need for greater cultural awareness, both in their personal conduct and in their intellectual understandings of Indigenous knowledge. These issues remain the focus of ethical guidelines today and yet it is apparent that there remain researchers and research funding bodies that fail to address these concerns (see Paul and Atkinson, 1999 for a critique of recent articles in the *Australian and New Zealand Journal of Public Health*).

Applying Ethical Principles

The suggested expansion of the ALSWH's main cohort through the inclusion of urban Aboriginal or Torres Strait Islander women would be required to adhere to the core ethical principles in the current NH&MRC's Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (1991). The following section discusses the broad headings of consultation, community involvement and ownership and publication of data as they relate to the ALSWH. These guidelines are however, currently under review.

Consultation

"An important first step is to identify what are the key issues and concerns as seen from an Aboriginal perspective...After all, who could know better than Aboriginal people what it is they have experienced and suffered over the years and what it is they want "fixed" and how best to fix it." Johnstone (1991;10)

The process of consultation required for the suggested expansion of the ALSWH to collect information from urban-dwelling Indigenous women around the country would necessitate consultation at national, state and local level. Current NH&MRC guidelines state that the Aboriginal and Torres Strait Islander community or an "appropriate community controlled agency able to represent the Aboriginal and Torres Strait Islander group which is the focus or content of the research" would need to indicate support/approval for the study. While these guidelines were originally drafted with remote communities in mind, the consultation process is equally important, if more complex, for urban populations. NH&MRC guidelines state explicitly that the use of the term "communities" encompasses Aboriginal and Torres Strait Islanders living in remote, rural *and* urban locations. They go on to explain that where no community exists in a geographical sense, community organisations may be appropriate avenues to conduct negotiations. It is clear both in the NH&MRC guidelines and in other ethical guidelines concerning Aboriginal and Torres Strait Islanders that "community" is relevant to all research and that individual consent alone is not sufficient to proceed with research. In the case of the ALSWH, one of the difficulties obviously lies in identifying a community organisation that is able to represent urban Indigenous women from around the country. It is unlikely that such a diverse group of women could be represented by a single organisation, and

appropriate consultation would involve a number of organisations and individuals. It is common practice in Indigenous health research to establish a reference group, inviting interested parties, including Aboriginal health workers, organisation representatives and community members, to ensure that a variety of opinions and views from within the community is expressed and that the research receives input from a wide range of sources (see Eades *et al.*, 1999). This attempts to avoid the situation whereby one single organisation or elder is assumed to represent a community with diverse opinions. Furthermore, the NH&MRC guidelines require that “Aboriginal and Torres Strait Islander women, as advised by the community, will be involved when research deals with women’s health issues” and alerts the researcher to the need to understand the cultural responsibilities and sensitivities related to “women’s business”.

For a national study, the consultation process would involve dealing with a collection of different communities; urban Indigenous women are by no means a homogenous population and the assumption that negotiations will consist of one Indigenous viewpoint and one academic standpoint which need to be reconciled is too simplistic. Henderson *et al* (2002), in discussing the situation in northeast Victoria, highlight the complexity of the consultation process in a single area:

Different Koorie organisations often have different expectations of outcomes, and levels of involvement, interest and commitment. Because of the holistic nature of research, many organisations are usually involved, with unclear boundaries and changing requests.

The consultation must begin with a discussion of the research topic itself. The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) guidelines (2000) note that it is essential that the community be given a reasonable amount of time to consider the research proposal and to discuss the importance of the proposed study. NH&MRC require that the community must indicate that the research is an agreed priority and that the study would be useful. Models of such collaborative work are provided by authors such as Dunne (2000), who published a detailed account of the early stages of research with urban Aboriginal groups. Dunne outlined a lengthy process of consultation and rapport building and noted that the research question developed out of these discussions and underwent subsequent refinement following initial interviews. For a national study, a flexible time frame and a genuine

commitment to negotiating research priorities would be required to obtain a wide base of support.

The establishment of study aims and objectives would represent only one of many phases in the consultation process; ongoing consultation is required. The AIATSIS guidelines state: “research projects should be staged to allow continuing opportunities for consideration of the research by the community.” The current structure of the ALSWH main study does not include mechanisms for consultation with Indigenous groups, nor does the established timeframe for data collection and analysis lend itself to this. The time from initial consultation to initial data collection in the field is estimated conservatively as needing 2-2.5 years for a complex study that would involve women from around the country (see for example the WA Aboriginal Child Health Survey). Furthermore it would require a number of staff from different parts of the country, skilled in community liaison, to ensure that consultation included all relevant parties. Establishing who can speak for whom is a difficult task (Oxenham *et al.*, 1999). Little (2000) has examined the complexities of defining “community” in Aboriginal contexts and argued that the assumption that community organisations are gatekeepers of their communities is problematic. In contrast, the AIATSIS guidelines state that the researcher must identify appropriate individuals and organisations for consultation and advise that “there is almost always someone to speak for a particular place or area”. It is evident that the exclusion of key individuals or organisations from consultation can have serious consequences for the support and participation a research project receives. The failure of researchers and funding bodies to appreciate both the time and the cost of consultation may lead to inappropriate budgets and timeframes for Indigenous research and result in pressure on communities, straining their relationship with investigators. These issues of multiple negotiations with numerous organisations have been highlighted here, not to imply that a national study of Indigenous women’s health is unfeasible in itself, but rather to point out the complex process of negotiation and consultation required.

Community Involvement

The NH&MRC guidelines discuss community involvement with specific reference to local community members being offered the opportunity to assist in the development and conduct of the research. The suggested study of urban Indigenous women would need to consider the opportunities for Aboriginal women or Torres Strait Islander women to be employed and appropriately compensated for their involvement in the research, for example as collaborators, research assistants, interviewers and interpreters. While the hiring of local Indigenous people as interpreters or interviewers alone is not sufficient demonstration of community participation, it remains an important element of Indigenous research. A research project that offers employment opportunities and the prospect of training and development of new skills in the community represents some reciprocity. As Indigenous groups continue to build capacity for research it is useful to consider how scholarships and research internships may be negotiated with the community, to ensure that the skills of research remain after the investigators have left. Likewise the issue of tangible benefit to the community can be seen to represent a sharing of the rewards that research brings. A study needs to demonstrate how the less material though no less important outcomes of research in Indigenous communities will be returned to the participants. FSI *et al.*, (1997) discuss the notion of Rights to the benefits of Research and eloquently describe the rewards that researchers receive from their work in Indigenous communities; these may include higher degree, scholarships, publication kudos, enhanced career prospects and academic status. These too must be shared with the participants, with appropriate compensation negotiated on a case-by-case basis and determined by community need.

The issue of compensation for participation in research warrants consideration. It has been suggested that the principle of avoiding harm includes consideration of the time spent in research and that researchers must take care to shape their research and select participants in a manner that spreads the burdens and benefits of the study (Mumford, 1999). This principle is especially relevant to over-researched populations such as Indigenous communities and should alert researchers and funding bodies to the demands that involvement in a study places on individuals and community organisations. There is anecdotal evidence from Aboriginal Medical Services (AMS) for example, of excessive burden from researchers who seek

assistance in the recruitment of participants (pers. comm. Aboriginal Health Research Ethics Committee SA). A careful balance, therefore, must be reached between the right and the need for community participation and the burden that this involvement represents. AIATSIS guidelines, for example, caution investigators that overall, “a researched community should benefit from and not be disadvantaged by a research project,” and prompts consideration of how to ensure benefit is returned to local participants. In the example of the AMSs or Aboriginal Community Controlled Health Organisations (ACCHOs) contributing their time and expertise, a reasonable expectation (in addition to adequate financial reimbursement) may include assistance to develop submissions based on research results, or support to conduct their own studies on identified issues of particular local concern.

Increasingly communities are developing their own protocols to govern the conduct of research. These involve a reasonable time frame for the communities to consider research proposals and to debate the benefit or harm that may result from the project, and to enable stakeholders to enter negotiations from a position of control and knowledge. A number of authors have commented on the lengthy timeframes required for initial and ongoing consultation in the community, the need to be cognisant of community responsibilities and the likelihood of delays and rescheduling if community/family matters arise which require attention (Hunter and Smith, 2000; Thompson, 2000). This is especially an issue for a study of women, as any research plan would need a realistic and flexible timeframe which accounts for the interruptions, delays and disruptions that can be expected when women, who bear a large degree of family and community responsibility, are called to attend to these personal issues.

This degree of community participation and commitment to local capacity building would represent a marked change in the conduct of the ALSWH, which currently has few of these issues to consider. Support and participation of Indigenous women in the ALSWH would not be secured unless an authentic partnership was in place that allowed women to contribute to the design, content, conduct, analysis and dissemination of findings. These conditions would be difficult to meet for a study with pre-determined priorities, whose methods have already been decided, and which is already underway with a broader group of participants. The suggestion to expand the ALSWH with more Indigenous women is inconsistent with the requirement for genuine community participation.

Ownership and Publication of Data

The procedures and protocols for ownership and analysis of data and publication of research results would need to be dramatically altered for the ALSWH to incorporate an additional Indigenous component and meet minimum ethical standards. For the purposes of NH&MRC approval, the research team would need to demonstrate their intentions to negotiate the release of data from the study, a willingness to engage communities in discussions regarding appropriate audiences and the content of peer reviewed articles for publication. Bearing in mind the complex consultation process it is likely that there would be a significant delay in releasing results and in submitting articles for journal publication. Communities require a reasonable amount of time to consider research results themselves, to discuss how to disseminate useful information to the study participants and local health professionals, and finally to negotiate a culturally sensitive and meaningful way to disseminate results to a wider audience. Communities are becoming increasingly concerned with the costs and benefits of publishing research results in peer reviewed journals and would need to be convinced of the advantages of releasing results to a wider audience. Anderson (1996; 163) poses the question, “How will published reports be interpreted by the mainstream press, and is there a risk that they will be misrepresented to add currency to traditional colonial stereotypes?” This is an important issue that requires further comment.

The Aboriginal and Torres Strait Islander Women’s Health Project, which has developed from the “special cohorts” component of the ALSWH, was confronted with this issue. Having collected data from several communities the research team found that some women were reluctant to have their data compared to one another, for fear of creating bitterness and tensions between communities. Furthermore, the women were unconvinced of the benefits of having the data of Indigenous women as a whole compared to the data which have been collected from other Australian women involved in the ALSWH or from other Indigenous women who participate in the ALSWH (Williams and Baigrie, 2002).

This reflects an international trend of Indigenous communities considering the potential harm which may result from the publication of their health data; O’Neill (1998) notes the increasing concern of Canadian Aboriginal groups, that a portrait of a

sick community may be used as justification for continued marginalisation and paternalism. These types of issues, if not thoroughly considered at the outset of the project, may present significant frustrations to the communities, researchers and funding bodies. Where the research team has contracted to project deliverables in the form of journal publications, they may be in a position of being unable to fulfil this commitment. Where communities cannot see the benefits in journal publication, they are likely to view the researchers' emphasis on this outcome as inappropriate and at odds with their own priorities. NH&MRC guidelines anticipate this problem to some extent and advise potential researchers that:

“If there is any reason to expect that there may be a misunderstanding between researchers and Aboriginal and Torres Strait Islander research subjects over the conduct of research, the ownership of raw data or the rights to publication of research findings, these matters must be discussed and negotiated and preferably agreed upon by both parties before the research begins.”

The suggested expansion of the ALSWH to include more Indigenous women would require all parties involved in the research (likely to include a series of reference groups) to understand and agree upon the ownership and the use of the data. The time required by community organisations to review research findings and to consider reports and articles for publication may be lengthy and researchers and funding bodies need to be aware of the likely delays that may result. The desire of researchers to have articles submitted in a timely manner for publication and the need of the Commonwealth Department of Health and Ageing to receive interim reports must be set against the reference groups' needs to consult with communities and to consider fully the consequences of publication, the degree to which participants or their communities may be identified and the possibility of misinterpretation of the research findings which may be harmful to the participants. Recent studies, which have produced successful outcomes in terms of publications, have in common an extensive involvement by reference groups in overseeing and/or co-authoring study reports and articles (for example Eades *et al.*, 1999; FSI and Kothari, 1997). In contrast, publication of ALSWH findings is led by the investigators in consultation with the Department of Health and Ageing.

Furthermore, the ALSWH is required to lodge data annually with the Social Science Data Archive and to make the data available to other researchers, subject to certain restrictions. Other major national longitudinal studies have similar

requirements to ensure accessibility of raw data to other investigators. Issues of ownership with respect to Indigenous data would make such access very problematic.

Beyond NH&MRC Guidelines

The NH&MRC guidelines have been criticised by various sources, and since their development in the 1991 a number of State and local ethical committees have been established to oversee the research involving Indigenous participants. Some communities have moved towards setting their own research protocols and are developing their own standards for ethical and responsible research. These protocols extend the general principles of the NH&MRC guidelines by ensuring cultural sensitivity and emphasis on local relevance and community benefit (Henderson *et al.*, 2002). Humphrey notes that the NH&MRC guidelines fail to address explicitly the issue of data ownership. Additionally there is limited consideration of ongoing surveillance of projects, and researchers are likely to view the guidelines as pertinent to the approval of the study but less relevant as an ongoing component of research (Humphrey, 2000). It is around these issues especially that Institutional Ethics Committees have sought to produce stronger statements and ensure more effective negotiating positions for themselves, which see researchers answerable to communities at every stage of the project.

There is a general sense reflected in the Indigenous health literature that the guidelines may have outgrown their usefulness in their current form (see Humphrey, 2000). There is a feeling that they are not contributing to the transformation of Indigenous health research and a number of communities, researchers and scholars have moved beyond these formal protocols to consider the more dynamic issues of Indigenous research. These are evident in the works of Eades *et al.* (1999), Williams and Baigrie (2002), Anderson (2001), and others who ask questions of their own and others research which moves beyond the NH&MRC guidelines to practical and philosophical issues of Indigenous enquiry.

Indigenous World Views

Adherence to Indigenous principles of research is both a matter of ethics and of human rights (Eades et al., 1999).

While formal guidelines for ethical conduct have been seen by many as a useful and necessary starting point to guide non-Indigenous researchers, others suggest that the emphasis placed on guidelines has in some sense served as a distraction from the broader debate about the conduct of research itself, the methodologies and methods that are presumed able to elicit information and produce meaningful outcomes. Smith (1999:118) has noted that legal definitions of ethics are based on Western beliefs about the individual, their right to consent and individualized notions of property. She argued, "...community and Indigenous rights or views in this are generally not recognised and not respected." Other Indigenous scholars are also questioning the very foundations of research and are demanding research that aligns with Indigenous ways of knowing. Winch and Hayward (1999; 26) discussed "Aboriginal Terms of Reference" and argued that these refer not to simplistic understanding of rules of research or guidelines for "doing business with Indigenous people" but rather is an expressed need to consider research from an Indigenous world view. Indigenous peoples around the world are recognising the role of research in self determination and are actively seeking to define the boundaries, set the priorities and inform the methodologies which are used to investigate issues concerning themselves and their communities.

"The development and conduct of research based on a methodology and a worldview that may not be shared with the potential 'subjects' can have negative impacts. Not only can it devalue the culture and understanding of Indigenous communities, but it can also mean the research will lack meaning to those it aimed to assist." (Dunbar et al., 2001; 23)

The ALSWH has been designed to consider biopsychosocial factors that contribute to adult women's health across the lifespan. The study has adopted a Western positivist approach to knowing and understanding health. It has successfully recruited and retained a very large cohort of women from around the country and as follow up surveys are conducted, the research team has been able to produce a series

of scientific papers that examine relationships between women's lifestyles, health behaviours, health outcomes and the use of health services over the life course. The mail-out survey technique used to collect data is focussed on the individual woman, and her experiences in the work, family, relationships, leisure etc. The size and random selection of the sample enables the investigators to make inferences about the health of Australian women, to compare the study cohort to what is known about women in other countries, and to provide recommendations about health policy and the delivery of health services.

This approach has value and merit in a Western positivist research environment. It does not, however, articulate with an Aboriginal or Torres Strait Islander worldview. Rigney (1997) stated that Indigenous peoples are likely to think and interpret the world differently, that their understandings and realities are different as a result of their different experiences, histories, cultures and values. Many of the negative research experiences of Indigenous communities in this country are related to the interpretation of data in isolation from their social context (Henderson *et al.*, 2002).

It is little wonder that the world's indigenous communities are apprehensive and cautious toward research 'ontologies (assumptions about the nature of reality), epistemologies (the ways of knowing that reality) and axiologies (the disputational contours of right and wrong or morality and values)'. Rigney 1997 citing Scheurich and Young.

Across a range of disciplines, the voices of Indigenous people can be heard demanding that their worldview be the basis of research that concerns them. The CAAC in its 1982 submission to the Australian Anthropologist Organisation's conference called for research to be conducted "within culturally intelligible and acceptable frames of reference" (Bourke, 1995; 48). The Koori Centre of the University of Sydney identified the need for research approaches to "reflect the communal collective system of communities rather than the individualised approach" (Bourke, 1995; 49).

To understand a woman's health from within an Aboriginal perspective one must understand her community, her family, her personal history, and the history of her people. From this perspective, to ask about health and well-being is to ask about the community. To recommend that Aboriginal women and Torres Strait Islander

women participate in a random, individual survey of themselves, independent of their community context, does not resonate with what women know to be the issues of their health. An Aboriginal women can not consider her own health without first reflecting on her family, her mother's health, her children's health, the health of her community, her culture, her environment. This is how she will understand her own well-being. This is her health.

Health is not just the physical well-being of the individual but the social, emotional and cultural well-being of the whole community.
National Aboriginal Health Strategy (1989).

Using a non-Indigenous research paradigm to attempt to measure health in other ways may lack context and meaning and thus be unable to contribute to local health solutions. If there is a need for governments to understand the determinants of health for urban Aboriginal women across the life span, it is apparent that any investigation must begin with Aboriginal women identifying what this means. The research outcomes must be considered thoroughly to ensure that this does not become an exercise in examining and reiterating what is already widely known. Any study of women's health must move beyond obvious comparisons, if for no other reason than that "it is not ethical... to carry out projects which describe what is already known" (Eades *et al.*, 1999:147). Only once the aims and objectives have been negotiated can appropriate tools for research be determined. This is the essence of community consultation, a process undertaken not simply to fulfil ethical requirements but rather to understand and conduct meaningful research.

Future Considerations

The international as well as local trends in Indigenous research point to increasing community control and conduct of research. Communities initiate health research themselves; they draw on the expertise and knowledge within their communities to determine research priorities, and they seek to understand health issues that affect them through Indigenous ways of knowing. This is consistent with the long-term goals of self determination (O'Neill, 1998; Humphery, 2000). There exists great potential for researchers (Indigenous and non-Indigenous) to collaborate with communities in seeking answers to health problems.

Any attempt to study Indigenous women longitudinally should only be undertaken with the explicit understanding that this is a dynamic area of research, one in which distinctive models and strategies for research are likely to evolve over time. Priorities in Indigenous research are currently under review. Community expectations of ethical conduct are likely to change over time, stakeholders will come and go. It cannot be assumed that agreements, consent and consultations that took place at the initial stages of a project will be sufficient at later stages. Study proposals must be responsive to the growing body of knowledge related to Indigenous methodologies and able to incorporate these into continuing research. It is only in the last twenty years or less that real challenges to the current knowledge bases and ways of acquiring knowledge have begun, and it is anticipated that as more Indigenous researchers enter academia there will develop stronger, more appropriate, more valid ways of researching health with Indigenous communities which will contribute to genuine solutions (Humphery, 2000). The preceding discussion has focussed heavily on the requirements of the researchers, the need for flexibility and a willingness to enter genuine collaborations, to modify and adapt the research process on the basis of community consultations. This practice however presents a challenge to established research processes and for it to be successful, funding bodies themselves will need to review their own procedures, to accommodate sometimes significant changes to the research protocol, and to acknowledge the difficulties of producing an ethical proposal prior to the consultation period.

In the context of the suggested expansion of the ALSWH it is clear that the incorporation of Indigenous methodologies into the predetermined framework would be very problematic without dismantling the current project entirely. In addition to the prohibitive ethical issues there are substantial logistic problems that are discussed in the next chapter.

Chapter 3: Methodological Issues

Introduction

The preceding chapter outlined the ethical issues that would arise from an expansion of the ALSWH and concluded that this would conflict with the principles of Indigenous research. Despite this, the current chapter examines considerations of sampling, data collection, analysis and publication of a longitudinal study of urban Indigenous women. It draws on recent longitudinal studies of urban Indigenous populations to identify logistical issues related to expanding the ALSWH and again argues against this proposal on the grounds of methodological and practical limitations.

In the following discussion there is consideration of some alternatives to the current study design. This is included to highlight the complexity of issues that would surround any proposal to conduct a longitudinal study of Indigenous health. It is not the intention of this report to suggest an alternative design. This is clearly a process that would require extensive community consultation and negotiation to develop suitable methodology.

The Design of the ALSWH is not Appropriate for Research with Aboriginal Women and Torres Strait Islander Women

In the original submission, it was noted that Aboriginal women and Torres Strait Islander women would require investigation to focus on areas of concern specific to their circumstances (The University of Newcastle, 1994). For example, the submission indicated that the investigation of time use would have to recognize women's roles in community participation and representation and explore the impact of these on health and well-being. Similarly, the issues examined in relation to life stages and key events were identified for Aboriginal and Torres Strait Islander women to include initiation, grandparenting, separation of children, relationship with the land, discrimination and prejudice, self-determination/reconciliation, and the social importance of serious illness in the family/community. These are issues that were not identified as important focuses in the main study. Furthermore, the submission stated that use of, and satisfaction with, health services is likely to be influenced by

culturally specific issues that require investigation such as language patterns used, avoidance relationships, level of empowerment and respect received.

It was apparent at the outset of the ALSWH that the health of Aboriginal women and Torres Strait Islander women would be influenced by culturally specific issues that would require separate consideration. It was felt that the needs of this population would not be adequately addressed within surveys designed for the main study and the rationale for a “special cohort”, as it was described, included the need to address different issues such as those outlined above. At the same time, investigators outlined the difference in sampling, recruitment and conduct that the Aboriginal and Torres Strait Islander study would require. The arguments in 1995 that supported the need for a “stand alone study” have only been strengthened since this time, with the increasing awareness and respect for Indigenous terms of reference in research and communities’ rising expectations for participation and ownership in research processes.

Choice of Age Groups

Subsequent submissions from the Aboriginal and Torres Strait Islander Women’s Health Project have reiterated the need for a separate study that is sensitive to the different circumstances and concerns which affect Indigenous women, both urban and rural. One of the fundamental concerns raised has been that the ALSWH age groups are unsuitable for use in Indigenous populations. The age distribution of the Indigenous population does not reflect the general population pattern in Australia, as demonstrated in Appendix 1. Indigenous women in Australia have an average life expectancy of 63 years, compared to almost 82 years for all Australian women. This demonstrates that it would have been inappropriate to attempt to recruit Indigenous women in the same age group as the old cohort of the main study (the participants were 70-75 years old at baseline and will be 79-84 years of age at the next survey in 2005).

Part of the rationale for the older cohort in the ALSWH included investigating issues surrounding widowhood and the move to less independent lifestyles with reductions in physical health. The average life expectancy of Indigenous males is currently 55 years (compared to 76 years for all Australian men), indicating that Indigenous women, at least those who have Indigenous partners, are likely to

experience widowhood much earlier in life. Furthermore, Indigenous people are recognized to have earlier onset of chronic disease and to begin accessing aged care services earlier in life than their non-Indigenous counterparts, indicating that decline in health and independence occurs earlier in this population.

At the other end of the age spectrum, the young cohort in the ALSWH (aged 18-23 at baseline in 1996 and 25-30 at the next survey in 2003) was chosen to investigate transitions into the workforce, movement into adult relationships, and new motherhood. Again the data for Indigenous women reflect quite different circumstances compared to the general population. In 1997, less than a third of Indigenous students remained at school to year 12, indicating that the majority of Indigenous girls are leaving full time education before they are 17 or 18 years of age, and are therefore facing issues of employment and unemployment at an earlier age than their non-indigenous peers. Similarly, the earlier age at first birth and higher teenage pregnancy rates (up to four times the rate for all Australian women) further support the need for a much younger cohort than the main study investigates if the same issues are to be explored (see Appendix 2).

The example of age and life stage provides a brief illustration of the inappropriateness of using a study designed for the general population to investigate health issues for Aboriginal women and Torres Strait Islander women.

Conducting a Longitudinal Study

The proposal to collect individual data on a longitudinal basis from Indigenous women requires consideration and debate. The National Aboriginal and Torres Strait Islander Health Strategy Draft (2001) notes that in spite of the amount of research conducted in communities, good quality health data are severely limited. This document indicates a need for research that investigates which factors contribute to the excess mortality and morbidity seen in the Indigenous population. Furthermore, it suggests that “different factors are likely to be more influential at different stages of the life cycle...”. These claims appear to support the need for a longitudinal study, the basis of which is its ability to detect changes over time, to investigate risk factors in the development of disease and the long-term impact of health interventions (Curtin and Feinleib. 1992). There is a paucity of longitudinal studies in Indigenous health, a situation that is reflected internationally. Stout and Kipling (1998:9) noted the

dominance of case studies and snapshot surveys in their review of literature on Canadian Aboriginal women. They recommended, “that priority be given to the development and implementation of longitudinal studies. Tracking key indicators pertaining to Aboriginal women over time is a research imperative.” While the usefulness of longitudinal data may be apparent to researchers and government departments, communities may be less likely to value this information. The decision to repeat surveys and collect the same data over a period of time must be guided by expectations that there will be some change in circumstances or responses. Indigenous health literature reflects considerable concern that the health indicators of Aboriginal people have in general undergone little change over the past decade (Ring and Firman, 1998), and there is a strong perceived need for less emphasis on descriptive studies of Aboriginal health status and more attention on action research involving community based interventions (Manderson et al., Holmes *et al.*, 2002; Thompson, 2000a; Humphery, 2000).

Moreover the notion of follow-up itself, of surveillance, of keeping track of people, watching, monitoring over time is one that must be considered in the broader cultural and historical context of Aboriginal and of Torres Strait Islander experiences. The collection of data about Aboriginal people has in the past played an integral role in colonial control of the Indigenous population in Australia (Dodson, 1994). The reluctance of Indigenous women to provide identifying data and to be tracked over time is likely to be a considerable hindrance to the conduct of a longitudinal study (See box 3).

Even if the participants do find this concept acceptable, the research team faces the difficulty of using key contacts for follow-up information. In longitudinal studies, particularly those concerning a mobile population such as urban Indigenous women, it is good practice to record a list of informants who may be approached to assist investigators in locating participants who have been lost to follow-up. Recent studies of vulnerable and/or mobile populations identify this process as core to the success of minimizing attrition over the life of the project (Wright *et al.*, 1995; McKenzie *et al.*, 1999). Holmes *et al.* (2002; 1270) recognize that as a consequence of past experiences with authorities, “Kooris often respond to requests for information with fear, distrust or anger.” The level of co-operation that researchers can expect from community members whom they approach seeking the whereabouts of the study

participants will be influenced by the level of trust that is established between the researchers and the community (Dennis and Neese, 2000).

While the practical and logistical considerations of following mobile populations have been discussed by a variety of authors (Wright *et al.*, 1995), a literature search for longitudinal studies in an Aboriginal or a Torres Strait Islander community yielded few results. It appears that this has not been a popular method for investigating health issues, case studies and cross-sectional surveys being more prevalent in the published literature. Five published longitudinal studies were found and are summarized below with reference to particular methodological issues encountered.

Box 1. Bibbulung Gnarneep Project (Eades et al., 1999)

The Bibbulung Gnarneep project represents a collaboration between the Derbarl Yerrigan Health Service and the TVW Telethon Institute for Child Health Research in Western Australia. Established in 1995, the project followed a birth cohort of 270 Aboriginal children and their mothers in metropolitan Perth (Eades et al., 1999). The study aimed to include all Aboriginal mothers living in Perth and giving birth during a 15-month period. Of the eligible mothers 87% were able to be contacted and 61% of these agreed to participate. The study involved face to face interviews and the project was staffed by Aboriginal women. The study involves data collection and analysis followed by immediate translation of results into community action. The application of findings has contributed to health promotion programmes at a community level, the training of local health workers and publication of brochures addressing issues such as SIDS risks and dental care. One of the interesting elements of this project has been the development of community-agreed protocols and procedures for this urban study and the extensive involvement of a community reference group (which met every 6 weeks) and co-authors the study publications. This study is considered by many as a model of effective community participation and research collaboration and is an indicator of the extent to which Indigenous research needs to be based on principles of authentic and respectful partnerships with communities regardless of their location.

Box 2. Living with Diabetes (Thompson, 2000)

The Living with Diabetes project was a mixed methodology study of non-insulin dependent diabetes in an urban Aboriginal community in Melbourne. Like Holmes' study (box 4), this involved a collaboration with the Victorian Aboriginal Health Service (VAHS). This participatory study demonstrates the extended period of consultation that often precedes good quality Indigenous research. The author spent eighteen months in negotiation with community representatives and community organizations prior to formulating a formal study proposal. The project included 38 in-depth interviews, several focus group discussions, and the administration of a face-to-face questionnaire with Aboriginal people living with diabetes. The author discusses the issues of recruiting, training and retaining Indigenous interviewers. One of the major challenges identified in this study was the balancing of research priorities with the community's desire for action or intervention. The study indicates that the development and maintenance of a strong partnership with the community required addressing issues of direct benefit to the community and including a community-owned component to focus on secondary prevention of diabetes. The author also discusses the limitations to achieving true collaboration, which include the relationship between researcher and funding body and specifically the requirement for study questions, aims and objectives to be approved prior to commencement of the study.

Box 3. The Aboriginal and Torres Strait Islander Women's Health Project (Williams and Baigrie, 2002)

Established as a component of the Australian Longitudinal Study of Women's Health, this project involved rural, semi-rural and urban communities in Queensland. A large-scale study operating over multiple study sites, this project was defined and contracted prior to appropriate community consultation (Williams and Baigrie, 2002). This represented a significant barrier for investigators and Manderson et al. 1998 have discussed the extensive negotiations that were subsequently undertaken to ensure community participation and support of the project. Originally intended as a longitudinal study of individual women, the methodology of the study was altered after consultation with communities. It was discovered that, "women felt the notion of individual health and its determinants made no sense" and a decision was reached to use the community as the unit of analysis (Williams and Baigrie, 2002). The study involved face-to-face interviews with approximately 490 Aboriginal and Torres Strait Islander women and trained local women in data collection. Through the communities' participation in the design and conduct of the research, it was established that some elements of traditional "longitudinal" studies were problematic or irrelevant for this population. For example, questions regarding mobility, previous place of residence, and intentions to relocate in the future were found to be particularly sensitive and indicate the need to consider the intrusive nature of this line of questioning in Indigenous populations. Likewise the original proposal to repeat surveys conducted at baseline met with resistance from the women, who felt analysis of the original data should inform subsequent surveys and allow investigation of identified issues. Among the successes of this project were the community's establishment of a Healthy Lifestyles Program in Cherbourg as a result of initial survey findings and the development of a data base system for Woorabina Health Services to enable the community to monitor its use of resources. This type of capacity building in research communities is an example of the reciprocity that Indigenous populations are appealing for from research partnerships.

Box 4. Aboriginal Health and Urban youth (Holmes *et al.*, 2002)

Holmes et al. (2002) describe a study initiated and carried out by the Victorian Aboriginal Health Service (VAHS) that tracked urban Indigenous youth in Melbourne. Following a child health promotion project, the community called for a new focus on the health of young people. Taking into consideration the younger age at which Aboriginal adolescents face issues such as finding work, pregnancy and coming to terms with identity, the study sought youth aged 12 – 25 years to investigate variables associated with risk and resilience in this population. Rather than operate through a hospital-based ethics board, the VAHS established an Institutional Ethics Committee (IEC) and registered it with the NH&MRC. The IEC was then able to approve the initial study design and give community consent and also to monitor the conduct of the study, receive complaints and act in an advisory role for the project. The authors recommend that future projects incorporate into the budget an amount to support the monitoring of ethical aspects of the study.

The research team hoped to use the VAHS patient register as a sampling frame, however the IEC declined this, indicating that patients had given their name and contact details for the purpose of medical care only and that this was not an appropriate use of that information. This is an example of genuine consultation with the community contributing to a sensitive and respectful decision being reached. The authors note that the “depth of feeling associated with privacy breaches in relation to identity or address can only be understood with a good knowledge of the history of discrimination and removal of children which Aboriginal people have experienced in the recent past”. The alternative strategy that was used was to develop a list of young people’s names for the purpose of the research using informal networks and snowballing techniques. This took a long time, raised awareness of the project, but after several months had produced only 400 names. The IEC was approached again with a request to send information about the study to young people on the database and inform them that their names would be added to the list of young people if they did not object, this resulted in a final list of 1116 names which formed the sampling frame. A sample of 425 was selected, 113 of whom were ineligible to participate, 104 were unable to be contacted and 29 declined to participate, leaving a total of 176 in the study. This example provides some insight into the challenges of obtaining a sampling frame in an urban setting and the time required to achieve this.

Data collection for the quantitative stage of the project used peer interviewers and, consistent with the other studies reviewed, the authors commented on the high turnover of interview staff, but felt that overall the use of peer interviewers was advantageous. The questionnaires were computer-administered with the option for participants to have the questions read to them while they entered their own answers. Follow-up surveys have yet to be conducted, however as this study progresses it may uncover useful techniques for tracking participants in this urban setting.

Box 5. Longitudinal Study of Indigenous job seekers (Hunter and Smith, 2000)

Hunter and Smith (2000) provide reflections and advice regarding longitudinal studies in Indigenous communities, with specific attention to sample design, retention of Indigenous interviewer and data quality. They summarise the lessons learnt in a Department of Employment, Workplace Relations and Small Business longitudinal study conducted in during 1996 and 1997, which was interested in participation in the labour market. The study was conducted in a range of urban areas, large rural areas and remote centers. It drew its sample from the Commonwealth Employment Services (CES) database and involved three waves of survey using face-to-face interviews (telephone interviews were occasionally conducted if the participant had moved to an area not covered by the survey).

Hunter and Smith (2000) describe the challenges in recruiting and retaining Indigenous interviewers and conclude that Indigenous interviewers are often more mobile and/or harder to replace than their non-Indigenous counterparts and the decline in Indigenous interviewers over the life of this study may have had implications for data quality. The study experienced an initial non-response rate of over two thirds, (these are people who were selected to be in the survey but could not be located or refused to participate) and noted that overall attrition rates were highest in capital cities and major urban areas. The authors identified two main impediments to achieving adequate data quality: low response rates, and data collection techniques that are not culturally appropriate. They stress that using Indigenous interviewers is no guarantee of high response rates and that telephone interviews should be avoided where possible, as they do not achieve a suitable response rate. Face-to-face interviewing is firmly recommended, noting however that this comes at a cost. Data collection, which took place from early 1996 to late 1997, was estimated to cost \$800,000. A total of approximately 7127 interviews were successfully conducted with 3171 respondents over the three survey waves (the study included a supplementary sample at survey two).

While each of these studies describes quite different experiences in conducting longitudinal studies, they support the notion that working with Indigenous communities requires unique approaches to research. Cultural sensitivity is more than a polite and respectful attitude; it is a willingness to engage new methodologies to ensure that research is both appropriate and acceptable to the communities involved. In the above examples the processes of ethical approval and of sampling and recruiting and conducting a longitudinal study were adapted to meet the specific requirements of the study population. The following section considers some specific methodological issues in greater depth.

Individual vs Community

“Individualism leads one astray, obscures important things and prevents the finding of that which one seeks - understanding.” Biggins (1999:48).

The issue of conducting an individual-based longitudinal study with Indigenous women was given thorough consideration at the outset of the Aboriginal and Torres Strait Islander Women’s Health Project and this report reiterates the conclusion of Manderson *et al.* (1998), who state, “A research model that selects out individuals and isolates health from the socio-historical context is seen as intrusive and threatening and as uninformative, unable to address the fundamental societal issues that concern the entire community... .Women’s views of social health are clearly at odds with the intentions, methodologies and matter of conventional longitudinal studies, which track individuals over time and which do not include interventions that are a precondition of involvement by Indigenous Australians.”

This is not an issue unique to the Aboriginal or Torres Strait Islander communities, but rather is reflected in the international literature on Indigenous research. The emphasis on the individual in the longitudinal methodology is often at odds with Indigenous perspectives on social organization. Smith (1999) emphasizes that it is a “Western” assumption that the individual is the basic social unit and promotes questioning of methodologies that assume the individual to be the appropriate unit of analysis. Biggins (1999) also considers the nature of the individual and compares Aboriginal and Western perspectives on this, demonstrating a need to bridge the different understandings of individual and group relations. In the domain of health in particular, communities have expressed clearly their desire to understand and address the social, environmental, historical and political determinants that impact on well-being. These issues which go beyond individual characteristics demand the attention of researchers.

The trend in Indigenous research is for communities to draw on Indigenous ways of knowing and to consider “Western/academic” research techniques such as longitudinal studies as just one option in a toolbox of research options. The advantages and the disadvantages of using an individual longitudinal approach will ultimately however require debate from Indigenous women themselves and a decision

regarding this could not be made without extensive consultation and Indigenous approval.

Sampling Frame

Considerable challenges face researchers in accessing vulnerable populations, which Flaskerud and Winslow (1998) define as “social groups who have an increased relative risk or susceptibility, to adverse health outcomes.” The issue of successfully locating Aboriginal and Torres Strait Islanders to participate in a research study is further complicated by the paucity of records and databases with Indigenous identifiers. The ALSWH used the Medicare (Health Insurance Commission) database as the sampling frame, which is infeasible for recruiting additional Aboriginal women and Torres Strait Islander women as there is no Indigenous identifier on this database. Similarly there are no Indigenous identifiers in electoral rolls. One option for creating a sample frame in the urban areas is to collaborate with Aboriginal Community Organisations and utilize their client database. It would be necessary to estimate the potential biases this could introduce. There would need to be a way to determine the percentage of eligible women not accessing these services and their likely characteristics. It has been pointed out that this type of sampling strategy may threaten the generalisability of study results (see University of Newcastle *et al.*, 1995).

While there are examples of successful research collaborations and a desire to strengthen the capacity of ACCHOs to conduct studies of their own (NACCHO, 2001), informal discussions and anecdotal evidence reveal differing levels of support for research within these organizations. In some areas of the country these organizations have been inundated with requests from researchers for assistance and are consequently reviewing their protocols for collaboration. While this process is being undertaken, organizations are likely to decline to participate in any new projects.

An alternative to using community organizations is a population-based sampling strategy such as the one used in the Western Australian Aboriginal Child Health Survey (unpublished). This was a statewide community survey that utilized a probability proportional to size sample, to select 731 census collector districts (CDs) from across Western Australia. Each of the CDs selected was then door-knocked to screen for eligible households to participate in the survey, and the interview was

conducted at that time or arranged for a later date. This process entailed approximately 14 months in the field collecting data and produced around 85% participation rate. A similar strategy is currently being used by the Australian Bureau of Statistics which is conducting an Indigenous Social Survey (for release in 2003).

A related option would be to sample from the Medicare database using only those postal areas that are known from the 2001 census to have high proportion of Indigenous people. In such urban areas, however, the proportion of non-Indigenous residents still greatly exceeds the proportion of Indigenous residents so that most of the women selected would be inappropriate to the goal of increasing the number of Indigenous participants in the ALSWH. Additionally Indigenous women living in other urban areas (say with fewer than 10% of Indigenous residents) would not be included in the sampling frame and this would introduce additional biases with respect to living conditions and access to services.

Any of these alternative ways of obtaining a sampling frame would need further consideration and community consultation. It is clear however that sampling for an additional cohort of Indigenous women would not be straightforward and a different sampling frame would be required compared to that used in the ALSWH.

Mode of Administration

The ALSWH relies on mail-out surveys for the vast majority of its data collection (with telephone interviews being conducted for those who do not complete the paper questionnaire and for some substudies). The typical survey is 20-30 pages in length and contains about 300 questions. These tools are developed and tested for readability with the general population.

The use of lengthy survey instruments such as those used in the ALSWH has been criticized as inappropriate for use with Indigenous Australians (Perkins *et al.*, 1995). Such instruments require a level of reading ability that cannot be assumed to exist in the target population of urban Aboriginal and Torres Strait Islander women. For example, in 1996 only 32% of Indigenous students remained in school to year 12 and in some areas only a quarter of those successfully completed the year (1996 National School English Literacy Survey, cited in Anderson, 2002). The 2001 Census data revealed that of Indigenous women over the age of 15 who are not in full time education, over 80% have not received an education beyond year ten. The use of

telephone administered interviews as an alternative to face to face interviews has been criticized by Hunter and Smith (2000) who suggest that telephone interviews produce lower response rates and if they must be used, this should only occur after trust and rapport has been established in face to face interviews. Aquilino (1994) also suggests that the telephone can increase social distance between the interviewer and respondent and exacerbates the difficulty of convincing participants of confidentiality. The problems associated with mail-out or telephone interviews appear to be supported in the research to date that overwhelming uses face-to-face interviews for data collection with Indigenous communities, both urban and elsewhere.

Confidentiality

Indigenous research requires consideration not only of individual confidentiality but of *community* confidentiality (Norton and Manson, 1996). The issue of naming communities and conducting analysis to compare communities to one another is one that must be addressed during consultation. Norton and Manson (1996) provide examples of the unintended consequences of research and the negative repercussions for the community when they were named as the site of the research. Researchers and government bodies should be prepared to have communities closely scrutinize the possible benefits of this type of information being released and consider the effects this may have on dissemination of results.

Content Validity of the Study

The suggested expansion of the ALSWH to include more Indigenous women implied an intention to use the surveys that have been used for the ALSWH. These surveys include scales such as the MOS 36-Item Short-Form Health Survey (SF-36) and the Center for Epidemiology Studies Depression Scale (CES-D), which would require considerable attention and possible alteration to ensure that the language and content of the scales were suitable for use with an Aboriginal or Torres Strait Island population. This in turn would involve additional methodological work to establish the validity of the revised instruments. Database searches and

inquiries to relevant organizations have failed to uncover previous studies that have addressed these issues.

Moreover, the general content of these surveys was not developed in consultation with Indigenous women, nor with any specific reference to Indigenous issues. They address a number of areas that are not necessarily appropriate for this population and additionally fail to investigate other areas of key concern for these women. It was this issue in particular that provided the rationale for the “special cohorts” at the outset of the ALSWH. Even if issues specific to Indigenous women were explored in a substudy of the ALSWH, rather than in the main surveys, the main surveys themselves are clearly inappropriate in terms of content and mode of administration. This is likely to impact negatively on any attempt to recruit and retain additional Indigenous women for the ALSWH. Combining data from newly recruited women with women recruited in 1996 would require very careful consideration of validity (as well as major logistical challenges).

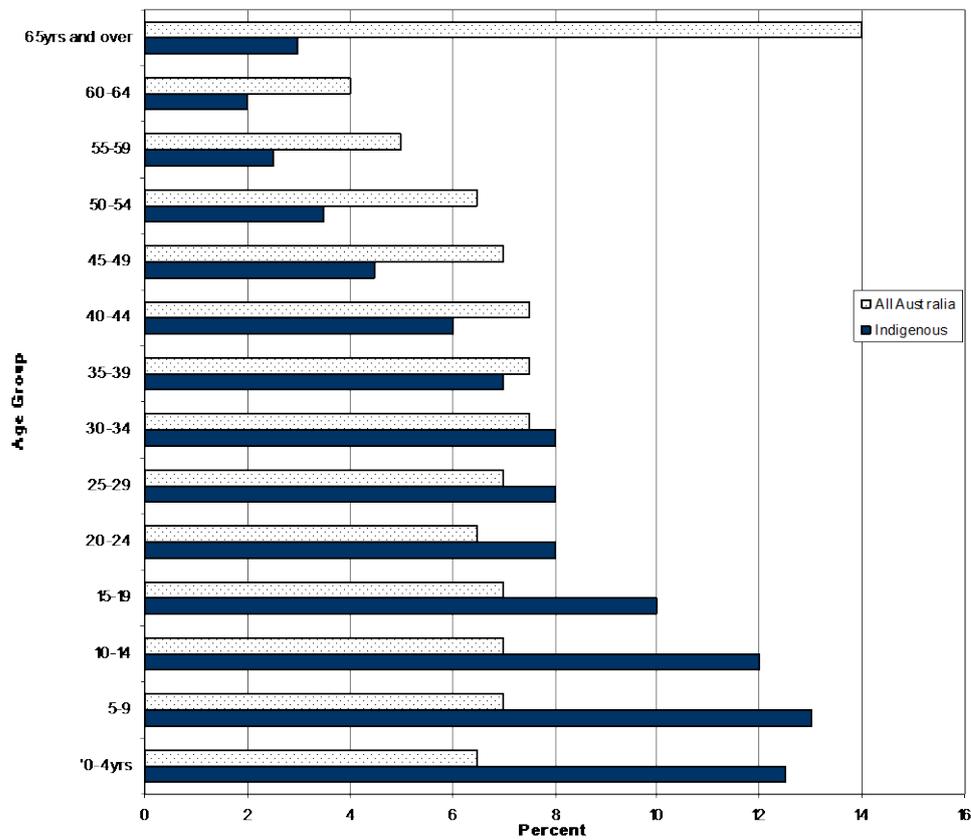
Conclusion

There are multiple barriers to conducting a complex, longitudinal study with a mobile population such as urban Indigenous women. These include the complexities of negotiating with a variety of community organisations, obtaining ethical approval from multiple committees, and the sheer logistics of recruiting and retaining a reasonable sized sample. Given an appropriate time frame and a flexible research approach, these barriers might be overcome; the key to this will be the support of women in urban communities. Where Indigenous women exercise ownership of the project, can see the benefit of this research, and feel they are engaged in a respectful partnership with the research team, the capacity to overcome logistical problems should not be underestimated. The review of a number of successful longitudinal studies demonstrates that this is possible. The proposal to ‘fit’ Aboriginal women and Torres Strait Islander women into the fixed structure of the ALSWH main study, however, is likely to encounter a series of serious methodological and logistical barriers, alienate those it seeks to assist, and ultimately prevent a successful outcome from this study. Given all that has been discussed in this report concerning the unique perspectives of Indigenous people, the need to develop different methodologies and to consider the specific circumstances that face Aboriginal women and Torres Strait

islander women, to suggest that they could be accommodated within the main study is not surprisingly offensive to some women (Fredericks, 2001). The use of surveys designed for the main study with Indigenous women is unlikely to be supported by communities who have not had the opportunity to provide input into their content and risks producing data which is not relevant to the communities it seeks to involve.

Appendix 1

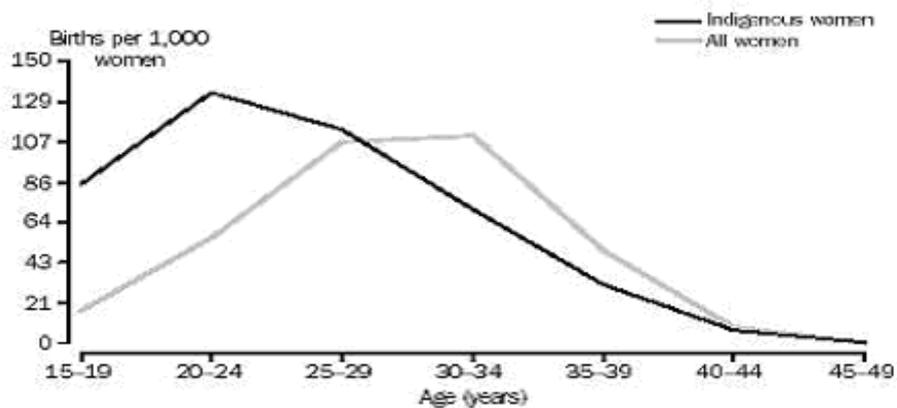
Female Age Distribution



Source: 2001 Census data

Appendix 2

Age Specific Fertility Rates



Source: Births Australia 2000. Abs catalogue no. 3301.0

Chapter 4: Recommendations

This report strongly recommends against trying to recruit additional Indigenous women to the Australian Longitudinal Study on Women's Health. As the purpose would be to provide data for health services, policy makers, planners and providers and for public health research specifically into Indigenous health issues, it would be essential to comply with NH&MRC and other ethical guidelines regarding research with Indigenous communities. These guidelines together with the established and emerging principles of Indigenous research require detailed ongoing consultation with communities who are subjects of the research from the beginning of the planning stages of any study. Their input to, and approval of, the methodology employed is necessary. As the ALSWH is already established the opportunity for this fundamental consultation does not exist (and in fact was not possible when the initial tender for the study commenced).

The authors do not see how this critical barrier could be overcome. But even if it were, the methodology of the ALSWH is inappropriate for the study of Indigenous health issues: the age groups of the cohorts, the sampling frame, the mode of administration, and the content of the main survey are all inappropriate.

It is noted, however, that acknowledgement of the need for a large scale study of the health issues of urban Indigenous women is likely to be welcomed by communities and health workers alike. Investment in a well-constructed, effectively negotiated study has the potential to produce much needed information on Aboriginal women's health and patterns of health service use.

This report has focussed heavily on the requirements of researchers; the need for flexibility and a willingness to enter genuine collaborations, to modify and adapt the research process on the basis of community consultations. However this also presents a challenge to the established research processes and would require funding bodies to review their own procedures and to acknowledge the difficulties of producing an ethical proposal prior to the consultation period. Policy-makers in particular need to re-examine methodologies used in mainstream studies and consider, in collaboration with communities, what are appropriate ways of gathering health information. This process should be informed by the work of the Research Agenda Working Group and ensure that any future project is aligned with the priorities for Aboriginal and Torres Strait Islander research.

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