5 Protocols, study design and questionnaire development

This chapter describes the aims, development and implementation of the surveys, from the initial contact made with the Cherbourg community, the community and ethical approval processes, through to the study design and methods. The results and discussions are presented in subsequent chapters. Only the methods of the surveys conducted in the field are included in this chapter; methods involving the use of archival weight growth data are presented in Chapter Seven.

The aim of the present study is to further understanding of variability of Type 2 diabetes within an Aboriginal community, through a survey of physiological and other variables that are considered independent risk factors of diabetes, a survey of lifestyle behaviours known to be associated with diabetes risk, and the relationship between early childhood growth and adult risk factors. It is hoped that findings from the present study will contribute to understandings of diabetes epidemiology more globally, in particular patterns of variation in diabetes prevalence.

5.1. Permission and community protocols

Cherbourg people in general are quite fed up with scholarly research, with the invasion of students and faculty members who have done every conceivable testing…many residents have openly expressed their strong disapproval of ‘being done over’, without often being able to see the benefit of the research (Koepping 1976, p. 31).

Several stages of approval had to be successfully negotiated for the present research, the Cherbourg Diabetes Study, to take place.

Cherbourg Community Council

Initial contact was made with the Cherbourg Community Council in October 1999 through a letter seeking permission to conduct a study of diabetes in Cherbourg. The Council replied that they had no objection to this study taking place. I spent two weeks in Cherbourg during the following December, to introduce myself and to inform the community further about the study. It was clear that diabetes was perceived as a significant health problem in the community, and research on diabetes within the community would be very welcome.
Cherbourg has had very many outside researchers conduct studies there over the years. Unfavourable feelings towards past researchers were reiterated numerous times at the commencement of my fieldwork by several community members. For example, the Cherbourg Council Chair had said that many researchers had appeared to arrive, collect data and disappear again without any tangible benefit flowing through to the community (Ken Bone 1999, personal communication). It was therefore important to demonstrate how the study could be advantageous to the community as a whole, in addition to benefiting the individuals who participate. This was done at many levels, initially through discussions with the community council, health workers, elders and eventually at the individual level. I attempted to make the study as relevant as possible both to individuals and the community as a whole, and worked to ensure that it could be seen that I had no hidden agendas.

I returned to Cherbourg in early March 2000 to undertake ten months of fieldwork research. The early part of this period consisted of familiarising myself with the community, following community protocols for approval and meeting with key figures in the community. I undertook a pilot survey, to establish whether there were any methodological problems and to make both myself and my reasons for being in the community well known. The design of the main survey was finalised and the questionnaire refined. The final three months of 2000 were spent intensively conducting the surveys. I returned to Cherbourg the following July for another month, to inform the community on the progress of the project analysis and to gather additional photographic and audio data.

As continuing feedback is highly important, preliminary research results were presented formally to the community at a seminar held in Diabetes Week in July 2001. Final results of the entire study and the thesis are to be presented to the community in November 2003 for discussion.

**Meeting the Elders**

Just before the commencement of the pilot study, I was invited to attend a meeting with the community elders. The Cherbourg elders meet as a group quite regularly at the school. First and foremost this is a social occasion, but is also used as a means to exchange information about the community, and facilitates discussion on the future directions of the community. It also aims to encourage links to be maintained between young and old. Meeting with the elders is one of the less formal, but by no means less important, community protocols, still firmly regarded as a mark of respect.
Attending the elders’ meeting provided the opportunity for us to meet and for me to explain my research. The elders approved of my presence in the community and the study I was to conduct. The elders were very supportive of the study as they see diabetes as a grave threat to the community. I provided some general information about the purposes of the study and my contact details in case there were any further questions, and asked them to mention the study to their family and friends.

**Cherbourg Health Action Committee**

The Cherbourg Health Action Committee meets about once a month to discuss the various projects that are taking place, and to set priorities for future programs and research. The members are made up of some of the staff at the Community Health Centre (Christine Stewart, Tarita Fisher, Harold Fatnowna), the Director of Health for the region (Peter Marr, Kingaroy) and members of the Cherbourg community. Before the main round of surveys could take place, the study had to be formally approved by the committee. I made a brief presentation to the committee in August 2000. By this stage I had been on fieldwork for five months and had already conducted the pilot survey, and so my intentions were already familiar to many people in Cherbourg. The benefits of a random survey were perceived as tangible, the intrusion into people’s lives was seen to be minimal and participation was emphasised as voluntary and only with consent. The committee approved the study.

**ANU Human Ethics Committee**

The study protocol was granted unconditional approval by The Australian National University Human Ethics Committee in January 2000.

**Fieldwork funding**

Funding for fieldwork was awarded through two bodies. Firstly, from the Faculty of Arts at The Australian National University, to assist primarily with travel expenses, purchasing of equipment and other costs associated with prolonged fieldwork. Secondly, a research grant was awarded by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), enabling the casual employment of two local Indigenous research assistants to help implement the questionnaires (Research Grant G2000/6417).

### 5.2. The pilot study

Diabetes is recognised as a major health problem by the Cherbourg community, so it is a research area that is seen as interesting and important to the community. The origins and
painful history of Cherbourg described in the previous chapter, however, and knowledge of the recent (and many would argue ongoing) poor treatment of Aboriginal people throughout Queensland and elsewhere means that wariness of outsiders, and occasionally overt suspicion, are understandable. The residents of this former ‘concentration camp’ remain acutely aware of past inequalities and abuses of basic rights. They are tired of being ‘used as guinea pigs’ (Markus 1982, p. 315), as the opening quotation of this chapter also intimates. I was therefore careful therefore to spend a significant time, before attempting the main survey, becoming a familiar face in Cherbourg, participating in community events, being seen as both available and approachable.

The best way to overcome these obstacles and fine-tune the methods was to conduct a pilot study. The main purposes of this were therefore as follows:

1. as a forum to enable people to meet me, and get to know me and my reasons for being in Cherbourg and for me to gain trust within the community. Above all this was to be a point of first contact with the study;

2. to test out and modify where necessary techniques to be used in the main survey, for example taking measurements using the most efficient and least intrusive or uncomfortable method; and

3. to alert people to the main survey which was to come and to highlight the benefits of participating, and rely on the grapevine to publicise the study further.

The benefits of taking part in the survey were framed both in terms of individual and community benefit. The primary direct individual benefit was the opportunity to find out whether they were ‘at risk’ of diabetes, according to the variables measured. For example, if blood pressure were above 140/90 or blood glucose (fasting or casual) above 5.5 mmol it was suggested that they discuss their results with their doctor with a view to follow-up testing.42

42 The intention of the survey was not to diagnose diabetes (and without medical qualifications and diagnostic tests this is not possible in any case), but to measure some important risk factors for the disease. Those considered to be at risk could then be advised to see their doctor.
On consultation with members of the community, through both formal discussions and casual conversations, it was decided that the pilot survey should take the form of a series of ‘screening days’. There were several benefits of such a method:

1. a public community event to raise awareness on particular issues, including health ones, is familiar to Cherbourg residents. In the past there have been such events held during Heart Week and Diabetes Week a few years previously (when a similar screening day was held), where information is readily available on improving health through a better diet and lifestyle. Bringing a survey like this into the public domain makes it much more of a community event, which is therefore likely to gain greater support than if it is seemingly targeted at specific individuals. It also becomes a common topic of conversation and people treat it as a social occasion;

2. diabetes is controllable and sometimes preventable, and a screening day survey provides the opportunity to highlight the direct benefits to the individuals who participate – that early awareness can mean better health;

3. screening days could be advertised as taking place at particular times so people would expect it; and

4. being held in a familiar and public venue that would mean those being surveyed did not have to have a stranger in their home.

An event such as a screening day where the focus is placed on early detection of diabetes might be considered unlikely to attract many people who have already been diagnosed. This turned out not to be the case. People who had been diagnosed with diabetes used the screening opportunity to monitor their own health.

Measuring fasting blood glucose for the pilot study was not feasible, given that many people would turn up ‘on spec’ out of curiosity, and it was expected that some screenings would go all day and people would turn up at times most suitable to them. Casual levels were therefore measured in the pilot study. Measuring fasting blood glucose was reserved for the main study when people had had the opportunity to prepare (Section 5.4.2).

5.2.1. Raising community awareness

A week before the very first screening day was due to take place I approached members of local organisations for permission to put up posters advertising it. These were placed at the respite
care centre, the AIM church, community health centre, 4UM radio station, hospital, school, day-care centre, Nurrunderi TAFE, sports centre, women’s refuge, and post office. The radio station ran regular announcements about the first screening day for the week leading up to it. I was also interviewed by 4UM about my research and my background at this time, enabling further opportunity for me to become known in the community.

The date of the first screening day, held at the health centre, was chosen through consultation with health workers\textsuperscript{43} with the criteria that it should be held early in the week, on an off-pay week, on a day when there were no bingo games and before the Easter weekend and school holidays. As the feasibility of conducting a later random survey was initially uncertain, the aim of these initial screenings was to target as many community organisations as possible to increase sample size and make the sample more representative of the whole community. Subsequent screening days were held at the Council works depot, the drug and alcohol rehabilitation centre, the aged care hostel, the primary school, the day care centre (for both parents and staff), and the AIM church in Cherbourg. Finally, a week was spent attending all the bingo games in Murgon in an effort to increase participation in the pilot study and to raise awareness among Cherbourg community members about the study.

5.2.2. Materials and methods

SPSS for Windows was the software package used for statistical analyses. The equipment used in the both the pilot survey and the main survey was as follows:

1. Speidel and Keller OSZ 5 automatic blood pressure monitor;
2. Roche Advantage blood glucose monitor and Advantage II glucose test strips;
3. Safe-T-Pro single use lancets;
4. KaWe 44440 height measure;
5. Tanita (model 1609) digital bathroom scales;

\textsuperscript{43} Tarita Fisher and Robyn Mcintosh.
Consent
Those who presented themselves at the screenings were given a consent form to read through and sign (Appendix A). The consent form explained the processes of each of the three stages of the study, and asked three separate questions: whether they consented to participate in the initial screening survey; for permission to link their birth and early medical records with the data collected during this study; and whether they would be interested in taking part in the later questionnaire survey. Consent was sought for all three parts to the study in case these participants would need to be contacted further. Each stage of the study was also explained orally to each participant. On the rare occasion when a participant could not read very well, the questions were explained in detail and the participant was asked if they agreed to each stage. In such cases, further emphasis was placed on the voluntary nature of the study, and permission was sought to circle their responses (yes/no) on the form, which were then initialled by the researcher. All were able to sign their name.

Participants were also offered a more detailed information form to take with them, which also included the researcher’s contact details (Appendix B). In the case of someone under 18 years, their parent or guardian were also required to sign the consent form.

Privacy
To ensure that individuals were not identified and their results remained private, identification numbers were assigned to each participant. The list of numbers assigned to names was kept separate from all other surveyed information, and only the identification numbers kept with the collected data. A similar process was used for the main survey, so that the list of names and identification numbers could subsequently be used to enable linking of survey data with archival records.

Measurements
The study aimed to measure the independent risk factors of diabetes of obesity, central obesity, blood pressure, in addition to age and family history of diabetes. Measurements taken were therefore height, weight, waist and hip circumference, and casual blood pressure. Casual blood glucose was used as an additional assessment tool. The same measurements were taken of participants in the main survey (although fasting glucose was used rather than casual glucose), which took place several months later. The methods of obtaining these measurements are detailed in 5.4.2.
5.2.3. Outcomes of the pilot study

The radio announcements were effective in raising awareness about the screening days. For example, one woman I gave a lift to a few days after the radio interview said that she had heard me, and subsequently came along for screening, and when I arrived at the post-office to put up posters the two women working there said that they had just been talking about the study and thought it was something that would benefit the community.

The sampling method used in the pilot study of targeting workplaces, community organisations and gathering places was not ideal, given its inherent lack of randomness. It was most useful, however, in reaching a range of sections in the community, and could have provided a sample of the community, while not random, that was reasonably representative should the subsequent random case-control study (Section 5.3) not have proved feasible. One section in particular is likely to have been under-represented in the pilot; young people who did not belong to any community groups or were not employed within the community, and who may not see diabetes as something they need necessarily be concerned with.

The pilot study was very effective in raising awareness and increasing participation in the main survey. Had I not taken the time to build these relationships, it is unlikely that the main survey would have proceeded as smoothly as it did. These were the greatest contributions of pilot study, ensuring community good-will towards me and generating interest in my research. This awareness and trust, in addition to the friendliness and competence of the research assistants, contributed to the high participation rates during the main survey.

5.3. The Cherbourg Diabetes Study

All subsequent discussion of ‘the study’ refers to the main survey conducted in Cherbourg, on which all subsequent analyses are based.

Suspicion and wariness of outsiders asking questions were well understood to be a likely barrier to obtaining a good response rate. While the pilot study had made a significant contribution to overcoming this by raising awareness of my presence and earning trust; simply the fact that I was a white researcher (from Canberra, a place often seen as holding substantial political power and not as part of the real world) is sufficient to make people wary. Some people, especially those unaware of the pilot study, could be hesitant.
To help overcome this, two local research assistants from the Cherbourg community were employed, to make initial contact and to implement many of the questionnaires. Potential participants would then be approached in the first instance by someone familiar, hopefully overcoming any initial mistrust, and hence increase the participation rate of the study. Maureen Weazel (aged 19) and Antonia Kirk (aged 20), were chosen through consultation with the community health centre, because they were both well known and liked within the community and were enthusiastic about the study. They were trained in how to select participants randomly from each household (Section 5.3.2), and how to explain the study to potential participants.

5.3.1. Integrity of survey responses

A research assistant who is known within the community may also introduce potential costs in terms of participation rates and bias in the honesty of responses. If, for example, the research assistant making contact belongs to an opposing family group or is disliked by the person who is being approached, their initial response to the survey may be more likely to be negative. The integrity of survey responses may also be at risk if the person asking the questions is known to the respondent. For example, questions with a perceived value attached, such as those about alcohol consumption, may elicit cautious responses if the participant has concerns about other people finding out.

There are two reasons why these potential confounds are limited in the present study. The first is that as they were introducing the survey, the research assistants made clear that responses would remain confidential. To what extent this was believed may depend on the relationship between the research assistant and the participant, but the two research assistants were chosen specifically because they had positive connections across sections of the community. The second reason is the apparent openness of people about their ‘bad’ habits and a willingness to admit behaviours that might not be seen as positive, either socially or in terms of health, such as heavy drinking. Most drinking seemed to be social, in that it occurs among groups and often outside, and at any hour. People freely admitted if they had been drinking (see Section 5.3.1) or were sometimes sick from drinking heavily (Section 8.2) and others seem at ease to give their opinion if they think someone has been drinking too much. This illustrates a prominent aspect of Cherbourg’s social milieu: everybody seems to know everyone else’s business. For example, if I approached a house where the person I was looking for was not at home, a neighbour would invariably call out to me and tell me of their whereabouts, and when they were likely to return.
5.3.2. Sampling
About two weeks before the main surveys began, I left a leaflet advertising the study with every house in Cherbourg (Appendix C). When the door was answered, I introduced myself and explained I was dropping off some information about the diabetes study that was going to be taking place over the coming months. If no-one were home, I slipped the pamphlet under the door (there are few letterboxes in Cherbourg – mail is collected from the post office). The purpose of the leaflet drop was to inform residents that the survey was about to take place, so they would be less surprised by a subsequent knock at their door. The flyers explained that the study had been approved by the Health Action Committee, what the survey would involve and that participation was voluntary. My contact details were included in case people had further questions.

The study is a case-control design, featuring known (i.e. diagnosed) diabetics as cases and randomly selected participants (never diagnosed with diabetes) as a control group. The control group was not age-matched with the diagnosed group. Before the study commenced there was strong anecdotal evidence to suggest that finding sufficient numbers of never-diagnosed people within the age-groups where diabetes prevalence is highest would be extremely difficult. This was confirmed during subsequent calculations of diabetes prevalence, where diagnosis is almost at saturation level in some age groups (see Section 6.1).

Cases
The cases were identified through the Cherbourg hospital database. This database contains codes for all diagnoses and treatments that have been made for all patients registered at the hospital. Information regarding chronic conditions is maintained in the hospital database, even if initial diagnosis was made elsewhere. Only people who had used the hospital in the last 5 years (January 1996 - September 2000) were included in the present survey. By considering only current patients, the time spent trying to find those who had moved away or had died would be minimised. The hospital is well used by the community, particularly as it functioned as an outpatient clinic in the absence of a general practice. By including all visits made in the last five years it is assumed that nearly everybody would be intercepted. In addition to this, because of the complications associated with diabetes, members of this group are even more likely to have visited the hospital during this time. The few diagnosed diabetics who had
recently moved to Murgon but still attended Cherbourg hospital were included in the survey as their use of the hospital implied that they saw themselves as part of the Cherbourg community.\footnote{Diabetics living in Murgon were not, however, included in the community prevalence estimates (Sections 6.1 and 6.3).}

The initial search of the database revealed a total of 73 women and 64 men registered at the hospital who were living with Type 2 diabetes. Of these, one woman and one man, aged in their late forties and early fifties, died before the main survey commenced. Seven women and five men were known to have left the community (two of the women had simply been visiting). Not all of the remaining participants were asked to participate. Six of the women and ten of the men were considered, upon consultation with the community health workers,\footnote{In particular, diabetes support worker Genette Simpson.} to be too old and infirm to be able to take part. Of the remaining, five women and two men were not found during the period of the survey, while five women and eight men refused to take part. This left a total of 49 of 54 women (ages 19-71 years, mean = 46.5 years) and 38 of 46 men (ages 27-79, mean = 49.3 years) who took part in the study. Participation rates among those with whom contact was made were thus 90.7% and 82.6% of diagnosed women and men.

Random sample

A control group was selected through random household sampling using a Kish grid (see Appendix D), where one person from each household, who had never been diagnosed with diabetes, was asked to participate. The community was worked through systematically, street by street, ensuring that no households were missed. Where contact was not made, the house would be returned to on a subsequent day at a different time, in an effort to maximise the chances of contact. Up to four such call-backs were made, for a total of 5 attempts. If contact was made with a household member other than the person required by random selection, a suitable time to return to see the desired person was usually arranged, rather than encouraging someone else to refuse on their behalf.

Households were chosen to form the foundation of the sample for two reasons. Firstly, selecting one member on a random basis from each household should produce a fairly representative sample of the community. Basing a community study on place of residence means that no section of the community (other than the small number living in institutions, see below) would be missed systematically, unlike a study that sampled only workers, or patients at
hospital, or those participating in the CDEP, for example. Each person over 18 years who was resident in Cherbourg and who had never been diagnosed with diabetes had a chance of being asked to participate. Secondly, the number of households within Cherbourg had the potential to produce a sample of a reasonable size and a size that was convenient given the scope of present study.

**Response rates and age-specific coverage**

There are 218 houses in Cherbourg,\(^{46}\) theoretically providing this number of potential controls. In 21 of these houses, however, the only people who were aged 18 or over were diagnosed diabetics, leaving a potential pool of 197. One of these houses did not have anybody over 18 living there and two were unapproachable because of the behaviour of dogs in the yards. No one was found at home in 35 out of the remaining 194, despite numerous call-backs on different days and at different times.\(^{47}\) Contact was therefore made with a total of 159 households that had somebody living there who was over 18 years and who had never been diagnosed with diabetes.

From these households, 62 women (aged 18-66, mean = 31.8 years) and 55 men (aged 19-65, mean = 34.5 years) participated in the study. This gives a response rate of 73.6\% for all houses where contact was made, or 60.3\% if those houses where no contact was made are included.

During the search for random controls, contact was made with a further 12 women who had previously been diagnosed with gestational diabetes, but who were no longer considered to be diabetic. These women also participated in the survey but are considered separately from both the cases and the controls. The mean age for this group was 31 years.

There were a further 23 people (partners or friends of the randomly selected person) who were present at the time of the survey who also wished to take part (13 women, mean age 28.4 years; 10 men, mean age 37.4 years). Although surveys were conducted, these additional people are not included in any of the analyses.

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\(^{46}\) The 2001 ABS Census counted 215 separate houses that were occupied, and 17 that were not occupied. This difference of 14 houses (from the 218 counted in 2000) is probably accounted for by new housing construction taking place during the year between the period of fieldwork and the Census.

\(^{47}\) A number of these houses were unlikely to have had anyone living in them at the time, for example, the 17 private dwellings that were unoccupied on Census night.
The total coverage through the random household survey of the total non-diagnosed adult population was about 24.7%, calculated by:

\[
\frac{n \text{ randomly selected participants}}{\text{total } n \text{ over 18 years} - n \text{ diagnosed people currently resident in Cherbourg}}
\]

Survey coverage by age and sex is shown in Table 5.1. Overall coverage was very similar between women and men. Men in the younger age groups were the group least likely to participate, while older residents were more likely to have been resident in institutions and were therefore missed in the household survey (see below). Other than those over 60 years, the lowest response rate was among young men aged 18 and 19, and the highest response rates were among women and men in their 40s. These differences are most likely to be due to perceptions about personal relevance of diabetes, against a well-documented background of less concern among young men regarding health (Connell et al. 1998). The probable reason for the poorer coverage of the over 60s is that this age group is much more likely to be living in an institution, in particular Ny Ky Byun aged care, and would therefore have been missed in the household survey.

Table 5.1. Age-specific coverage of community members. Random household survey (minus women who had had gestational diabetes)\(^a\)

| Age group | Females | | | Males | | |
|-----------|---------|-------|---|-------|---|
|           | Total   | n participants | % coverage | Total | n participants | % coverage |
| 18-19     | 19      | 5                 | 26.3        | 17    | 1                 | 5.9        |
| 20-29     | 93      | 25                | 26.9        | 82    | 17                | 20.7       |
| 30-39     | 63      | 18                | 28.6        | 64    | 21                | 32.8       |
| 40-49     | 33      | 11                | 33.3        | 37    | 14                | 37.8       |
| 50-59     | 21      | 2                 | 9.5         | 10    | 1                 | 10.0       |
| 60+       | 21      | 1                 | 4.8         | 14    | 1                 | 7.1        |
| All ages | 250     | 62                | 24.8        | 224   | 55                | 24.6       |

\(^a\) Totals for age groups calculated using the 2001 Census of Population and Housing (ABS 2002a) (see Section 6.1)

Both the pilot study and the pamphlet drops undoubtedly helped to increase rates of response to
the survey. The length of my presence in the community, my openness about the study and my personal involvement worked to improve opinions of such studies from those formed by past experience. In particular there was one instance I was frequently told of involving a diabetes study set to take place in 2003. I was told the researchers from this study (from a major Brisbane hospital) had last been in touch with the community several years previously, after a very brief period of contact, and no information had since flowed back to either the participants or the community. Residents were disappointed to learn of a recent paper published by the research group citing ‘ongoing community consultation’. People’s willingness to participate in the present study demonstrates, however, that mistrust caused by the past poor consultation practices of others is not necessarily universally perceived as applicable to future research and researchers.

Given the size of the community and the method of sampling, the number of participants was in statistical terms fairly low. A large sample has the potential to yield much more statistically powerful results, and to detect subtle differences between groups. For differences to be found statistically significant in the present study, they would therefore need to be substantial. Chapter 7 explores these issues of detectable differences and sample size.

**Over-sampling**

Many of the households yielding a random control participant also contained one or more people who had been diagnosed cases, leading to some level of over-sampling of households, i.e. someone else from that household was also a participant in the study. This is unlikely to reduce the representativeness the participants in the study of the community as a whole; the random sample is still random among those who had never been diagnosed, and the majority coverage of diagnosed participants was 80% to 90% which suggests that any sampling error in this group would be small.

**Institutional living: people staying in residences other than households**

Cherbourg has an aged care hostel and a drug and alcohol rehabilitation centre. There are between approximately eight and 15 residents staying at each of these at any given time. These forms of accommodation were not included in the random household survey. If each had been treated as a single ‘household’ then only one participant from each would have been asked to participate.
Mobility

One difficulty in conducting a random household survey over a period of several months is the mobility of individuals. In Cherbourg some people move between houses regularly, perhaps staying with one friend or relative for a few days, weeks or even months at a time. Often people talk about ‘staying’ at a place rather than living there, and their stay might be very short or long-term. Thus the composition of any given ‘household’ might be remarkably dynamic even over a short period, and many are not necessarily shared by a traditional nuclear family.

5.4. Developing and administering the survey

The survey was designed to seek the maximum amount of information about clinical, social and lifestyle factors which may influence risk of diabetes, while causing minimum disruption to people’s lives. Consent was sought from potential participants using a similar form and procedure as in the pilot study (Appendix A). For reasons of privacy and confidentiality, participants were assigned identification numbers and names were not used on survey forms. There were two parts to the survey, a questionnaire and a risk factor assessment.

5.4.1. Part one: the lifestyle questionnaire

Nutrition, physical activity and other lifestyle behaviours such as alcohol and smoking are established factors affecting the three modifiable biological independent risks of diabetes: obesity, central obesity and hypertension. The purpose of the questionnaire was to assess some basic features of nutrition, physical activity and lifestyle which are likely to affect these risk factors, with a view to determining which behaviours contribute most to diabetes risk in this community. People’s openness to modifying their health-related behaviour was also assessed to determine whether diagnosis of diabetes motivates people to make critical changes.

Which social and lifestyle factors may put people at greater or lesser risk of developing diabetes? Is there potential for people to change some of these practices? The aim of the questionnaire part of the survey was to gather as much useful information about trends in lifestyle behaviours within the community that might contribute to diabetes risk. Although the main intention of this study is to understand variability within the Cherbourg community, comparisons with other populations are useful in situating this knowledge, consequently some general questions were derived from previous Australian studies, where noted below.
A major criterion of the survey was to keep it simple and minimise intrusion, so as to gain maximum participation from community members with as little disruption to their daily lives as possible, while obtaining information in sufficient detail to be useful.

The majority of the questionnaire items were tick-a-box questions. Although this does not facilitate the gathering of in-depth information as might be possible from more open-ended questions, the survey had to be easy and quick to complete in order to achieve maximum participation. More qualitative information was gathered less formally during the lengthy fieldwork, and this is used to add depth to the information gathered from the survey responses. Some open-ended questions were also included in the questionnaire.

A draft of the survey was discussed with Cherbourg community nutritionist Tarita Fisher, and with other community members, to ensure its relevance and appropriateness to the Cherbourg community, in particular whether or not people were likely to feel comfortable with certain questions, such as those on alcohol use and body image. As the voluntary nature of the survey was emphasised throughout, it was decided that these more sensitive questions would remain.

In an attempt to reduce the length of the survey to a manageable size, some questions regarding income and the number of people living in the household were omitted. The number of questions included in the questionnaire was deemed the maximum consistent with retaining the co-operation of participants.

The questionnaire was divided into several short sections: general health, nutrition, lifestyle, sociodemography, and body image. There was an additional section for women to complete and another for those with diagnosed diabetes. The questionnaire could usually be completed within 10 to 20 minutes. Forms were either left with participants to be completed and collected at the time of the risk factors assessment (usually the next morning, see Section 5.4.2) or the questionnaire was administered orally by either myself or one of the two research assistants. Self-administration and oral administration occurred in approximately equal proportions, with no apparent systematic differences between the two methods. All seven sections of the questionnaire are provided in Appendix E.

**General Health**

The first section of the questionnaire consisted of six questions concerning health, family history of diabetes, and perceived stress.
Cunningham and colleagues (1997), in a national survey of Indigenous Health, found that many reported better health than might otherwise be expected from the long-term conditions, recent health-related actions and disabilities also reported. They suggest that health is a ‘social construct with multiple dimensions’ (Cunningham et al. 1997, p. 24) of which only disease is identified in the biomedical model. Self-assessed health status is therefore open to a significant level of subjectivity; different people might have differing ideas about what components make up health, including mental, social and cultural factors, as well as the physical (WHO 2002).

A global health question, such as ‘in general would you say that your health is excellent, very good, good, fair or poor?’ is potentially sufficient as they correlate well with multi-item assessment questionnaires (Cunningham et al. 1997, p. 1). However, a universal question such as this can be affected to a degree by recent health, for example whether they have felt unwell in the last week or two. This question was therefore followed by a more specific one asking how many times the person had been sick or unwell in the past 12 months. This was to determine whether there was any correlation between the global measure and a slightly more quantifiable and objective one (although such a question is potentially subject to recall bias: those who felt they had poorer general health might recall a greater number of specific episodes of illness).

Questions about stress were included because there is growing evidence that stress is associated with metabolic disorders at some level, whether through reduction in homeostatic glucose control in people with diabetes or by acting through possible prenatal changes, for example, to the HPA axis (Section 2.5). High levels of perceived stress has also been cited as extremely prevalent in Aboriginal communities (for example, Sibthorpe 1988), and may therefore have some significant bearing on diabetes risk, at both individual and community levels. Psychosocial ‘stress’ is, of course, highly subjective. The questions used were modified from Cohen et al. (1983); participants were asked how stressed they had felt about particular issues over the previous year. The responses were rated on a scale from 0-4 (not at all, slightly, moderately and very). They were also asked what action they usually take when they do feel stressed about something. This was to determine whether there were any differences between diabetes risk groups in how they subjectively perceive stress, and in their usual methods of coping with stress. For example, whether or not the usual response to stress of those at risk is more likely than lower risk individuals to be to ‘do nothing’.
Nutrition

Nutritional habits are very complex to assess (Franceschi et al. 1995). The usefulness and validity of any nutritional survey depends heavily on its intended purpose. There are a great variety of methods for assessing dietary intake: weighing all foods that are to be consumed (weighed food diaries), which can be very accurate but highly intrusive; keeping a food diary where participants are required to write down everything that they eat over a specified period of time, which may be accurate but participants have to keep it with them and remember to add to it whenever they eat, which can be very disruptive; 24-hour recall, which can be very useful if it is accurate (snacks for example may be easily forgotten), but does not assess habitual food intake. Store turnover, as has been used successfully as a measure of nutritional intake in some remote Aboriginal communities (for example Lee et al. 1994), is not an appropriate method to use in this study given the choice of shops available to residents. In addition, assessment was intended to distinguish between patterns of consumptions of individuals, rather than provide an overview of average community consumption. A food frequency questionnaire (FFQ) was chosen for this study.

FFQs attempt to assess habitual food intake rather than intake over a short period of time such as over a single day. There are two components to the amount of food that is habitually consumed – how much is eaten in a sitting (serving size) and how frequently it is eaten. Heady (1961) established that frequency of consumption was the more important of the two in measuring habitual consumption. Some surveys try to combine the two, providing examples of standardised portion sizes and asking how often and how many. Given the necessity of keeping the survey as short and simple as possible to minimise the burden on participants, only the frequency of consumption of particular food items was included in the present study. Simple food frequency questionnaires such as this are sufficient to indicate individuals’ patterns of habitual food intake (Buchorn 1995).

The FFQ used in this study was adapted from one used for the Australian Fitness Survey (Commonwealth of Australia 1995), with several alterations. Fruit and vegetables were treated as two separate items, because it became clear during fieldwork that people who eat one do not necessarily eat the other. Low-fat as well as full-fat dairy foods were included, as were white
bread, wholemeal bread, soft drink and diet soft drink, and bush tucker as a separate category. These additional items were included because of their specific relevance to diabetes. People with diabetes are generally recommended to avoid fatty foods, white bread, and soft drink and other foods are used to substitute for these (low-fat foods, wholemeal bread, diet soft drink). Bush tucker was included separately as a measure of ‘resilience’ to acculturation and because several studies have shown that the composition of traditional diets can lead to metabolic improvements (Section 2.3.2) while more Western-style diets have been shown to be associated with greater diabetes risk (van Dam et al. 2002). A further item that was added was a specific question about take-away foods, as these can be a regular food source for some.

A 19-item food frequency questionnaire was thus developed, with seven possible frequency responses, ranging from ‘never or a few times a year’ to ‘few times a day’. These were then coded to give the approximate (conservative) weekly frequency of consumption, following the method of Dobson et al. (1997), so that:

- Never or a few times a year = 0.01;
- About once a month = 0.25;
- Several times a month = 0.75;
- Once a week = 1;
- A few times a week = 3;
- Once a day = 7;
- Few times a day = 10.

Further questions were asked about missed meals, to determine what kinds of eating patterns people had, since this may influence diabetes risk or be affected by diagnosis. Participants were asked whether they sometimes missed meals, how often they missed a meal and the main

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48 Wholemeal (‘brown’) bread includes wheat bran and so has a higher fibre content than white bread, without necessarily using the whole grain.
49 ‘Soft drink’ is non-alcoholic, carbonated and heavily sweetened (e.g. Coca-Cola, fizzy lemonade). ‘Diet’ soft drink is artificially sweetened.
50 Bush tucker refers to food traditionally gathered and hunted.
reasons they might miss a meal. The frequency of missed meals were coded in a similar fashion
to food frequency, where:

Less than once a month = 0.1;
Once a month = 0.25;
A few times a month = 0.75;
Once a week = 1;
A few times a week = 3;
Several times a week = 5;
Every day = 7.

Thus the type of FFQ used in this study does not investigate serving sizes and therefore it does
not distinguish between individuals who may eat relatively small amounts of a certain food at a
time and those who consume large amounts (Willett 1994). The purpose of this questionnaire,
however, was to gain an insight into habitual patterns of consumption of a variety of foods,
rather than to estimate the quantities of each specific food, or of specific nutrients. Focusing on
frequency alone also avoided confusion and poor estimates of serving sizes.

Indigenous people have, as a group, relatively low SES in comparison with other Australians.
Income tends to be low, and there are often a greater number of dependants within a household
(ABS 1997, 2002a). It has been demonstrated in other populations that reduced nutrition
security can be positively associated with overweight and obesity among adults and children
(Alaimo et al. 2001; Townsend et al. 2001). Household nutrition security – whether people
have enough to eat and feel they have access to sufficient food – was assessed by asking
whether participants ever worry about not having enough food.

Usual dietary intake can change over time, and so current diet may not reflect intake at the time
diabetes developed. All participants were therefore asked if they had made any changes to their
diet in the last five years, and participants with diagnosed diabetes were asked if they had
changed their diet since diagnosis (see below).

Participants were also asked about whether they regularly miss meals, how often, and the main
reason for missing a meal. This was to establish whether certain groups had more regular eating
patterns than others, and whether missing meals regularly relates to risk of diabetes. The
reasons people tend to miss meals or eat irregularly may also be relevant to diabetes risk or management.

Participants were asked whether they thought their own diet was generally healthy. This was to determine where there might be potential gaps in nutritional knowledge that could subsequently be addressed. As knowledge and behaviour are not necessarily equivalent, participants were also asked whether they would be willing to change their diet if it would make them healthier, and if they had changed their diet in the last five years for health reasons. This was also aimed at gaining some insight into what ways nutrition might be improved in the future. For example, if people think they eat healthily but are also willing to improve their diet, perhaps an appropriate and sufficient focus would be on emphasising which foods make healthy choices, and most importantly, ensuring that they are accessible.

The means to improve diet also need to be available. Fresh food availability and affordability in Aboriginal communities has been the subject of many studies, including the Healthy Food Basket Access Survey in Queensland (Leonard et al. 1999). The Cherbourg shop carries very little in the way of fresh food, but acts mainly as a take-away (Section 4.4.6). Few Cherbourg residents have their own car. Approximately 60% of households have no car or other motorised transport\(^{51}\) and there is no public transport (only one person regularly rides a bicycle between Murgon and Cherbourg). Participants were asked where they usually do their shopping (Cherbourg, Murgon, Kingaroy or elsewhere), and how they usually get there. They were also asked if they would change where they shopped if suitable transport were available.

**Lifestyle and physical activity**

The lifestyle section of the survey contained 14 questions, primarily about physical activity, smoking and alcohol consumption.

The first question was aimed at gauging community and group opinion about personal risk of both diabetes and heart disease, adapted from a question regarding heart disease in *Active and Inactive Australians* (Commonwealth of Australia 1995). Participants were asked how likely they thought it was that they would develop these diseases, on a four-point scale from ‘not likely at all’ to ‘very likely’ (in addition to an ‘already have it’ option for those diagnosed, and ‘don’t know’).

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\(^{51}\) Calculated from number of households without a motor-vehicle (ABS 2002a).
An 8-point scale for assessing physical activity level was adapted from Dowse *et al.* (1990). Again, simplicity was paramount in determining how physical activity was to be assessed. Activity was divided into leisure activity and occupational activity, each worth a maximum of four points. Participants were asked if they regularly went walking or did some other light outdoor activity such as gardening (light activity), and whether they regularly played sport for more than 30 minutes and how often (heavy activity). These questions to ascertain activity level were based on those from *Active and Inactive Australians* (Commonwealth of Australia 1995).

Those classified as being sedentary in terms of leisure activity (score 1 of 4) did not undertake any regular outdoor activity, such as gardening or walking, nor play any sport. Light activity (score 2) was assigned to those who regularly went walking, worked in the garden or did some other light outdoor activity, but who did not play any sport. Those who undertook active sports, such as cycling, jogging, netball or football on one or two days per week were designated as moderately active (score 3), while those considered heavily active (score 4) played sport on three or more days per week. This technique has also been used by (Collins *et al.* 1994). These were then added to occupational activity levels (see below), also on a scale of one to four to produce a total physical activity score out of eight.

Occupational activity was based on main occupation, for example unemployed scoring 1, office workers and those undertaking home duties scored 2, CDEP workers and light trades scored 3, while builders and heavy labourers scored 4. This rather crude scale nonetheless provides a reasonable and simple measure of activity with a minimum of questions.

How people perceive their level of activity and their fitness in relation to others might influence whether they are motivated (or could become motivated) to change their behaviour. These questions on physical activity and nutrition in particular relate to the Transtheoretical Model of Change or ‘stages of change’ model used for a number of lifestyle factors to assess individual readiness to modify their behaviour. The stages in the model are precontemplation, contemplation, preparation, action, maintenance, and relapse (Zimmerman *et al.* 2000). In short, stage of change acts as a mediator in lifestyle behaviour modification; people are unlikely to increase their physical activity if they do not perceive there to be a need or if they are lacking in the means to do so (Zimmerman *et al.* 2000; Mau *et al.* 2001; Ronda *et al.* 2001). Recognising the stage that individuals are in for different healthy lifestyle behaviours means that education and encouragement can be targeted at an appropriate level.
Participants were asked whether they considered themselves to be more, less or about as active as others of their age and sex, and whether they thought themselves fitter, less fit or about the same as others. Ronda et al. (2001) found those who were not aware of their physical inactivity (the ‘precontemplation’ stage in the model) were less likely to consider increasing activity levels than those who realised their activity levels were low (the ‘contemplation’ stage). Responses to these questions might further help in future community education programs. For example, if people perceive themselves to be just as active or more active and with a greater level of fitness than their peers, it may be more difficult to educate them to become more active.

Questions on tobacco and alcohol consumption were also included as these have significant bearing on factors contributing to diabetes risk. Cigarette smoking can contribute to CVD and may directly contribute to diabetes risk through tobacco’s role as a potential stressor. Participants were asked whether they currently smoked and how many cigarettes per day, and whether they had ever been a regular smoker.

Alcohol may also be a potential diabetes-related physical stressor, or heavy consumption may contribute to diabetes risk through excessive intake of refined carbohydrates. Participants were questioned both on how often they drank alcohol and how much they usually consumed on a day when they did. These two questions were drawn from Active and Inactive Australians (Commonwealth of Australia 1995). This was to gain some insight into drinking patterns within the community, and the particular contribution these might make to diabetes risk.

Frequency of alcohol consumption per week was coded similarly to the questions on food and missed meals, so that:

- Don’t drink alcohol = 0;
- Less than once a week = 0.5;
- On one or two days a week = 1.5;
- On 3 or 4 days a week = 3.5;
- On 5 or 6 days a week = 5.5;
- Every day = 7.

Amount of alcohol consumed per drinking day was coded into approximate (mean) number of drinks, so that:
1 or 2 drinks = 1.5;
3 or 4 drinks = 3.5;
5 to 8 drinks = 6.5;
9 to 12 drinks = 10.5;
13 to 20 drinks = 16.5;
More than 20 drinks = 20.

As duration of obesity affects diabetes risk and reducing obesity can improve metabolic control of diabetes, participants were asked whether they had lost or gained weight over the last 12 months, and by how much. Onset of diabetes is sometimes accompanied by weight loss, and insulin resistance increases propensity to accumulate fat. Such a question might also reveal whether there were groups which are more or less aware of their own body’s responses to their lifestyle, and whether recent – and perhaps rapid or substantial – weight gain or loss had an effect on diabetes risk.

Participants were asked whether they had made any recent changes to how much exercise they do. These were aimed at determining which groups might be most likely to have adopted health education messages, and whether these changes had affected diabetes risk, and even which of diet or exercise modification might be most important in potentially reducing diabetes risk, or at least which of these is more achievable. As with the nutrition section, participants were also asked whether they would be willing to make changes to their exercise regime for health reasons.

**Sociodemography**

A woman who is born small or fails to thrive as a child is likely to have children who do the same (for example, see Dugdale et al. 1990a; Alsop-Shields and Dugdale 1995). The conditions where a participant’s mother was born may therefore have a significant bearing on a participant’s own past or present health status, given the possible intergenerational effects described in Section 2.4.3. Geographical difference in infant mortality rates was the primary variable related to subsequent adult health examined in the original Barker group study (Barker and Osmond 1986), used as a proxy for poor conditions. Some Aboriginal settlements in Queensland had extremely high infant mortality during the period when many of the
participants’ mothers would have been growing up. Participants were therefore asked where both they and their mother were born.

Birth order may also have an effect on birthweight – later born children tend to be heavier at birth than first born children (Section 2.4.3). Participants were asked how many children their mother had had, and where they fell in the birth order.

Potential differences exist in nutritional, infectious and psychosocial factors between children who grew up within the dormitory system and those who were camp kids. Participants were asked whether or not they lived with their natural family throughout their childhood, and if not, then the reason for this. This was aimed at establishing whether growing up in the dormitories – or at least absent from family – was associated with long-term health effects manifesting as diabetes risk in adulthood.

In Westernised countries diabetes is much more prevalent in groups with lower SES (Section 2.2). Does this association occur at a community level, one which as a whole falls into a low SES category? To determine whether there might be such variation within the community both level of education achieved and type of occupation were included in the survey, along with how many hours were worked per week. Type of occupation was also used to establish the level of occupational physical activity (see above).

**Body image**

People’s perceptions of their own bodies may be both a motivating and de-motivating force for improving health. Western medical ideas of what is normal or healthy in terms of weight range may have little relevance in some contexts, as perception of overweight is, at least partly, relative. Participants were asked whether they were happy with their body shape. Body image was further investigated on three simple items: whether or not they thought their body shape was normal, healthy and attractive. Participants were also asked what a healthier and more attractive body than their own might look like: fatter, thinner, taller, shorter, more or less muscled. Does a healthy body have similar attributes to that which is attractive? In an attempt to ascertain whether people would prefer to look healthy or attractive, they were then asked which of these choices (fatter, thinner etc.) they would themselves prefer to be.

**Women**

As diabetes may have its origins in the prenatal environment, women were asked to complete an additional section of the questionnaire about their reproductive history. Participating women
were asked how many children they had had, and how old they were when they had their first baby. They were also asked whether they were currently pregnant (waist circumference was not included in analyses for pregnant women) and whether they had ever been diagnosed with gestational diabetes. Women who had been diagnosed with gestational diabetes, but were not currently diabetic, were treated as a separate group in the analyses.

As quality of antenatal care affects birth outcome, women were asked whether they received adequate advice during pregnancy about having a healthy baby, and what could have been improved about this advice.

**Diagnosed diabetes**

Participants who had been identified in the hospital records as having diagnosed diabetes (not gestational) were asked to complete an additional section of the questionnaire. Participants were asked how long ago they were diagnosed with diabetes. They were asked what they had been told, if anything, about what caused it, and also what they themselves thought might have caused it. This was to gain some understanding about where locus of control might lie in community awareness of diabetes. If, for example, people are inclined to think they will get diabetes because it is in the family, they might be less willing to try to have a healthier lifestyle than if they think it is primarily a lifestyle disease, and hence somewhat avoidable.

The questionnaire asked which complications the person had or had suffered from in the past. This provides an indication of the morbidity burden diabetes places on individuals and the community, and suggests which additional health services from visiting professionals might be most beneficial.

The survey included a question on whether the person was currently taking medication for diabetes, and whether they could briefly describe how the medication helps with their diabetes. The latter part was aimed at highlighting any gaps in patients’ knowledge about their treatments, and whether understanding something about their medication means they are more likely to take it, or perhaps are better able to control the disease. Participants were therefore also asked whether they take their medication exactly as prescribed. This was aimed at determining whether there is a particular section of the community who might be most at risk from complications arising from poorly controlled diabetes.

Participants were asked what, if any, advice they were given about diet and exercise at the time of diagnosis, whether they had changed their diet or exercise regime since being diagnosed, and
whether they feel these changes had been beneficial. This information may be useful for determining whether newly diagnosed diabetics are given sufficient or appropriate information, and whether this information means they are more likely to have tried improving their lifestyle practices.

5.4.2. Part two: diabetes risk assessment
Not all widely recognised risk factors were found to be supported strongly enough in the NHMRC (2000) analysis for them to be considered to confer an independent risk. The factors that they found to pose a significant independent risk of Type 2 diabetes were age over 35 years, obesity, centrally distributed fat, hypertension and family history.

The method of measurement used in the survey to quantify current risk of diabetes were chosen based on the following five criteria:

1. measures obtained should give a reasonably accurate indication of individual risk;
2. impact on participants (discomfort, intrusion, disruption, time) should be minimised.
   The equipment used in the study therefore had to be extremely portable, so that participants could be met at their houses or work places rather than being required to make their way elsewhere;
3. maximum participation, arising out of (2) above;
4. I could undertake all physiological measures myself, thus eliminating potential for inter-observer error; and
5. instant results for immediate feedback to each participant.

Hence, some compromises were made between the most clinically accurate methods and what was pragmatic for an epidemiological study in this field situation. For example, a portable glucose monitor was used rather than sending blood samples for laboratory analysis, ensuring that immediate feedback could be given to participants.

The measures undertaken were fasting blood glucose, blood pressure, height and weight to obtain BMI and waist and hip circumferences. These last two were initially selected so that WHR could be calculated, but in the analyses waist circumference alone was used, an issue which will be discussed in more detail below. The equipment used was the same as in the pilot study (Section 5.2.2). There is sufficient evidence for each of these measures (other the WHR),
with the addition of age and family history, to be considered independent risk factors for diabetes (NHMRC 2000).

**Fasting blood sugar level**

Recent guidelines for estimating the prevalence of Type 2 diabetes suggest that fasting glucose alone is sufficient, rather than 2-hour oral glucose tolerance test (OGTT, or glucose challenge) (de Courten et al. 1998; NHMRC 2000). Some ‘borderline’ cases may only be detected using an OGTT. Testing fasting glucose requires very little of the participant; participation rates would have been significantly lower had the participants been required to consume a glucose drink.

Testing fasting blood sugar level (FBSL) has the additional benefit that it does not involve the participant having to wait around or return at a later time, and there is more leeway on the exact timing of the test. For example, if a glucose challenge is administered and the participant asked to come back in two hours, there is the possibility they may delay their return, or be less than enthusiastic about waiting or having to make an additional trip. A procedure such as this is time-consuming and, more importantly, risks non-compliance.

The FBSL test (and the rest of the diabetes risk assessment) for each participant was arranged to take place before they had breakfast and at a time most convenient for them, usually for the morning immediately following the questionnaire. Sometimes this was at 5am; many people in Cherbourg start work early in the morning, such as those working at the abattoir or at the council works depot. The study needed to fit in with the participants’ schedules, so they would not be kept waiting to eat or to have their morning tea or coffee.

At the same time as the risk assessment appointment was arranged, participants were instructed not to have anything to eat or drink after ‘tea-time’ the previous evening, other than water or black tea or coffee without sugar. Each participant was questioned at the time of the BSL test whether they had had anything to eat or drink that morning. In the majority of cases they had remembered not to eat or drink anything. On occasions the participant had forgotten, or became hungry earlier than the scheduled time and felt they could not wait, or in a few cases they had been drinking alcohol through the night or in the morning. If the participant had eaten or had had something to drink, a new time was made for the following day, and the instructions not to consume anything were repeated. Occasionally this occurred three or more times in a row. The reasonably relaxed atmosphere throughout the study, the relationship of trust that had been built up, and my willingness to minimise inconvenience contributed to what I believe was honesty in
Protocols, study design and questionnaire development

In this area. In the interests of obtaining the most accurate results possible, I made it clear that it was not difficult for me to come back another day and that it would only take a moment. In other words, people did not mind telling me things like, ‘sorry love, I just forgot’, or ‘I been drinking’. If the person had already eaten because they were feeling hungry I would try to make the new time for a little earlier in the day. Between approximately five and ten participants were usually seen each day, at a pre-arranged time between 5am and 10am, mostly between Monday and Friday but sometimes at weekends.

FBSL was measured to the nearest 0.1 mmol, using capillary blood obtained from a lancet prick to the side of a finger-tip. The device used to measure blood glucose was a portable blood glucose monitor (Advantage), as used for home monitoring. Although NHMRC (2000) recommend against using glucose monitors for performing diagnostic tests as they lack the accuracy of laboratory testing, this was most practical method in terms of expense, timely feedback to participants, and logistics. It was also not intended as a diagnostic tool, but was used to make a reasonable assessment of diabetes risk relative to others in the community. The standard for glucose monitors is that they are accurate within 10% (NHMRC 2000). The same glucose monitor was used for each participant and was calibrated daily. For fasting samples, venous and capillary measurements do not differ significantly (NHMRC 2000).

In line with the considerations for ethical approval of this study, it was recommended to participants with a fasting glucose reading above 5.5 mmol/l that they discuss the result with their doctor.

**Blood pressure**

Blood pressure was measured with an automated monitor, thus reducing the potential for observer error. Systolic and diastolic blood pressure (mmHg) and pulse (beats per minute) were measured with the participant sitting and having rested for approximately five minutes. During this time participants’ dates of birth were confirmed and they were asked where they were born, and chatted with me about the study.

Participants were asked to relax and rest their left arm on the table, and not to move it for the duration of the test. As a blood pressure measurement can be uncomfortable, participants were advised of this and were asked to inform the me if the test became too uncomfortable, in which case the test would be stopped immediately. This occurred on only a couple of occasions. On a few occasions the test was not completed in a first attempt due to a reading error – usually because the participant had moved his or her arm during the test or the monitor had difficulty
detecting a pulse (this was a source of great amusement). If an error occurred, a subsequent test was performed after several further minutes rest.

A problem which became apparent during the pilot survey was the dimensions and structure of the blood pressure cuffs. There were two available sizes, an adult cuff and an extra large cuff. Although the adult cuff was sufficient in absolute size in many cases, it was designed for a very cylindrical upper arm rather than a more conical shape. It became apparent that fat deposition in the participants often concentrates on the very upper arm, with marked thinning towards the elbow. This was particularly the case among women. This observation fits with previous research on the tendency for a more central pattern of fat deposition among Aboriginal people (for example, Dugdale et al. 1980; O’Dea et al. 1993). The extra large cuff was also made for a more cylindrical upper arm, and was often too big. As the extra large cuff also took longer to inflate and produce a reading, it prolonged the discomfort of participants. Therefore the smaller cuff was used wherever possible. Additional velcro was adhered to the cuff, before the main survey commenced, making the fit better and more secure on more conical arms. The result was a much better fit and reduced discomfort for participants.

As with fasting blood glucose, participants whose blood pressure reading was high (over 140 mmHg for systolic or 90 mmHg for diastolic pressure) were advised to discuss the result with their doctor.

**Overweight, obesity and patterns of fat distribution**

Height and weight were measured so that BMI could be calculated. Standing height was measured to the nearest 0.5cm with a portable stadiometer, which was constructed in the field by attaching the commercial stadiometer (designed for attaching more permanently to a wall) to a long plank of wood in the appropriate position. This was then held against a vertical surface such as a wall, aligned against a door frame or the posts holding up an outdoor shelter. Participants stood straight and tall as possible with arms and shoulders relaxed, with their feet together and their head placed in the Frankfort Plane (Duggleby and Fall c.1999). Where footwear was worn, the height at the heel was adjusted for. The scale was read in as level position as possible to avoid a parallax effect.

Weight was measured to the nearest 100g using digital bathroom-style scales. Where light footwear (such as thongs) was worn, no adjustment was made. Where heavier footwear was worn, weight was adjusted (700g for joggers, 1400g for boots). The majority of participants
removed their footwear before their height and weight measurement. No adjustments were made for clothing, which was generally light (t-shirt and shorts or dress).

Waist and hip circumferences were measured to the nearest centimetre, over light clothing. The widely accepted method of obtaining a waist measurement is at the smallest horizontal level between the xiphisternum and the umbilicus (Dowse et al. 1991b). During the pilot study, this technique was not found to be practical in this population. The central pattern of fat distribution among the participants meant that the smallest circumference at horizontal level was in many cases difficult - if not impossible - to determine, especially without involving a level and duration of physical intimacy that could easily cause embarrassment or discomfort to the participants.

To ensure therefore that the measurement technique remained as consistent between participants as possible, and for the survey to proceed efficiently with minimal discomfort or inconvenience, the waist measurement was taken at the level of the umbilicus. Participants were asked to hold the end of the tape on their ‘belly-button’, while I held the other end and walked around the person to meet the end held by the participant, ensuring the tape was horizontal. The level of the umbilicus has been used in previous studies for waist circumference in women and men in the Netherlands (Seidell et al. 1988), in Japanese-American men in Hawaii (Huang et al. 1997), in US men (Houmard et al. 1991), and in 11 year-old Greek Cypriot children (Savva et al. 2000). The umbilicus has also been used as the level of cross section for computerised tomography estimates of abdominal fat in Japanese women (Kanai et al. 1990) and 11 year-old children from the UK (Fox et al. 1993). Hips were measured from the side in a similar fashion, over the part of the buttocks that yielded the maximum measurement.

In the following chapter, estimates of diabetes prevalence in the community, both diagnosed and undiagnosed, are calculated. The prevalence of each risk factor is also presented.