

# Melbourne Collaborative Cohort Study Databook

(MCCS / Health 2020) Baseline Data

## Volume 1: Clinical



Leading  
the fight...

Melbourne Collaborative Cohort Study  
Databook  
Volume 1: Clinical

The Melbourne Collaborative Cohort Study, also known as MCCS and Health 2020, is a program of the Cancer Epidemiology Centre of The Cancer Council Victoria.

Citation: *Cancer Epidemiology Centre 2008. Melbourne Collaborative Cohort Study Databook Volume 1: Clinical. Melbourne: The Cancer Council Victoria.*

Volumes in this series are:

*Melbourne Collaborative Cohort Study Databook: Demographics*

*Melbourne Collaborative Cohort Study Databook Volume 1: Clinical*

*Melbourne Collaborative Cohort Study Databook Volume 2: Health and Lifestyle*

*Melbourne Collaborative Cohort Study Databook Volume 3: Diet and Alcohol*

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ISBN: 978-0-947283-83-4

Melbourne Collaborative Cohort Study Databook

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June 2008

# Melbourne Collaborative Cohort Study Databook Volume 1: Clinical

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# Preface

This is one of four volumes in the series Melbourne Collaborative Cohort Study Databooks, which reports on data gathered at baseline in the Melbourne Collaborative Cohort Study (MCCS), also known as Health 2020. In this series of volumes we report the baseline information on:

- attendance information
- clinical factors
- health and lifestyle
- diet and alcohol.

The MCCS is a large and ambitious study, which is already providing significant information and helping people to understand more about how they can reduce their risk of cancer and other diseases. It has been a challenge and a joy to work on this study, which promises to generate much valuable information.

Our aim in publishing these baseline data is to enable researchers and other interested people in Australia and elsewhere to understand the data collected as part of the study.

We describe each variable collected at baseline as well as the data format and data label for each variable. For all categorical data, we provide frequencies and cross-tabulations. For all continuous data, we provide frequencies and cross-tabulations as well as box plots by sex, country of birth and age group.

We have tried to make these volumes as user-friendly, clear and concise as possible. Please contact us if

you have any suggestions for improvements to future databooks on the MCCS. We welcome your feedback on these volumes.

I and all of the researchers wish to thank the thousands of people who volunteered to be part of the MCCS. These people have chosen to help to advance knowledge about cancer and other diseases, at some inconvenience to themselves, and we thank them for so generously giving their time.

We also thank the interviewers who have patiently and carefully interviewed the many thousands of volunteers. Many other skilled staff at the MCCS have enabled the study to proceed efficiently and we thank them for their contribution.

Finally, we wish to express our appreciation to the organisations that have supported the study financially. These include the National Health and Medical Research Council, VicHealth, National Institutes of Health, Prostate Cancer Foundation, Sir Edward Dunlop Foundation, Australian Brewers' Foundation, and the National Breast Cancer Foundation. Our great thanks to The Cancer Council Victoria, which has been the host organisation for the study, has housed many of the researchers and has provided ongoing financial support since the study began.

**Prof Graham G Giles**

Director, Cancer Epidemiology Centre and  
Chief Investigator, Health 2020, Melbourne, Australia

# Section I:

## About the MCCS

The Melbourne Collaborative Cohort Study (MCCS) is gathering information about diet, lifestyle and other factors from a large number of Melburnians. The information is enabling the MCCS researchers to test various ideas about the relation between diet and lifestyle and diseases that cause suffering and premature death, especially cancer, cardiovascular disease and type 2 (non-insulin-dependent) diabetes.

Our aim is to discover whether there are modifiable dietary and lifestyle factors leading to such illnesses. It has been estimated that over one-third of all cancers may be due to dietary factors. We are also investigating possible interactions between these factors and common variants in genes.

‘Participating [in Health 2020] creates awareness in your health and enables you to be aware of any pitfalls, like the links between being overweight and cancer. The link between diet and disease is very important and the more is known, the more prevention can occur.’

– a **Health 2020** participant

### An explanation of some terms

The MCCS is a **prospective** study, which means information about diet and lifestyle was gathered at the start (baseline) and then periodically over time. This series of four databooks reports on the baseline data collected during the recruitment phase of the study, between 1990 and 1994.

It is a **cohort** study, which means that a group of individuals is followed over time and the occurrence of one or more outcomes (e.g. cancer, type 2 diabetes or cardiovascular disease) is recorded or measured over time. The MCCS is one of Australia’s largest prospective cohort studies.

The MCCS is an **epidemiological** study. The objectives of epidemiological research are to:

- identify diseases for which epidemiologists want to know the causes or risks
- study populations to find out which people have the disease and which people don’t
- look at factors common to people who have the disease and who don’t have the disease
- then combine this with other scientific knowledge to work out which factors may have caused the disease or helped to prevent it.

The Melbourne Collaborative Cohort Study is also known as **Health 2020** and was previously known as Health 2000.

### How the MCCS began

What is the role of diet in the development of cancer, cardiovascular disease, diabetes and other chronic and life-threatening illnesses? How do we research this question?

The researchers who initiated this study wanted to contribute to scientific understanding about the link between diet and lifestyle and certain diseases, and were keen to explore the possibilities presented by Melbourne’s mix of migrants. It had been shown in research in the 1980s that migrants from Southern Europe were less likely to die from cardiovascular disease and certain cancers even some decades after arriving in Australia. The MCCS researchers wanted to

discover whether this was due to their diet and other lifestyle factors. It is also possible that a residual dietary effect continues to offer protection, even though these migrants' risk of some cancers and cardiovascular disease increased with their residence in Australia.

Including a large proportion of migrants in the proposed study, argued the researchers, would mean a wider range of foods would be represented. This would make associations between dietary factors and any disease outcomes clearer than with a limited range of foods.

The researchers began planning the study in the mid-1980s. Planning took several years. It included developing dietary questionnaires and other measurement tools, extensive pilot and feasibility studies and thorough review by international experts.

Work at the pilot stage included:

- recruiting 900 Greek, Italian and Australian-born volunteers to test questionnaires and techniques
- considering alternative designs
- promoting the study within the migrant communities
- developing, translating and testing questionnaires into Greek and Italian
- planning and coordinating survey methods
- designing and testing the food frequency questionnaire (pilot version)
- organising clinics for the clinical measurements
- organising biochemical analysis of blood samples
- planning for appropriate tissue storage facilities.

Among the experts consulted was Sir Richard Doll (Oxford), who died in 2005: in his life he contributed significantly to epidemiological cancer research. Also consulted were Prof David Zaridze (Moscow), Prof P Piettinen (Helsinki), Prof Tony McMichael (Adelaide),

Prof Bruce Armstrong (Perth), Dr Robert McLennan (Brisbane), Dr John Potter (Adelaide), Dr Graham Colditz (Harvard), Dr Ole Jensen (Denmark), Prof Dimitri Trichopoulos (Harvard), Dr Calum Muir (IARC), Dr Jean Hankin (Hawaii) and Prof Larry Kolonel (Hawaii).

The researchers attended workshops with other epidemiologists, nutritionists and cancer specialists to discuss the proposed study, and organised an international conference in Melbourne in 1988, which was attended by distinguished epidemiologists from around the world with experience in this field of research. Through its history, the MCCS has benefited from the knowledge and input of collaborators in Australia and internationally.

An extensive literature review formed an important part of the planning. The researchers reviewed the literature on diet and disease studies and observed a number of problems, including poor measurements of food intakes, limited ranges of dietary exposures and bias problems in retrospective studies. They concluded that most of the problems encountered in earlier studies would be overcome by following a large group of people prospectively, measuring diet before disease presented and enrolling a group with a large range of dietary intakes.

The researchers submitted a scientific proposal to the Executive Committee of the Anti-Cancer Council of Victoria in 1989 (the Anti-Cancer Council of Victoria is now known as The Cancer Council Victoria and is abbreviated in this document to 'the Cancer Council'). The proposal reported on piloting and consultation undertaken to date, and included a comprehensive rationale for the study.

The Cancer Council approved funding for the study; this funding was subsequently supplemented by grants and funding from other organisations and foundations (see later in this section).

## The founding researchers

The original scientific proposal was submitted jointly by researchers from the Cancer Epidemiology Centre of the Cancer Council, Monash University, the University of Melbourne and Deakin University.

The original researchers were:

Chief Investigator: Dr Graham Giles

Senior Principal Investigators: Dr John Powles (Monash), Prof Kerin O’Dea (Deakin) and Prof Richard Larkins and Dr John Hopper (Melbourne)

Principal Investigators: Dr David Hill, Dr Joanne Williams, Mr Paul Ireland and Mr Damien Jolley (Cancer Council); Dr Dimitri Ktenas (Monash); Ms Ingrid Coles-Rutishauser (Deakin); and Dr Joe Proietto (Melbourne)

## Governance, reporting and staffing

Researchers such as those listed above have taken a scientific role in the study; the management and administration of the MCCA is the responsibility of the Director of the Cancer Epidemiology Centre and the Advisory Board to the Cancer Epidemiology Centre.

In addition to researchers, interviewers and clinic support staff, the MCCA is supported by other staff employed by the Cancer Council, including staff with expertise in statistics, nutrition and epidemiology. We also rely on coordinators for the Australian, Italian and Greek-born groups, nurses, data collectors and laboratory assistants.

## How it is funded

The MCCA has been supported since its beginning by The Cancer Council Victoria. It has also gained funding in

the form of grants from the National Health and Medical Research Council, VicHealth, National Institutes of Health, Prostate Cancer Foundation, Sir Edward Dunlop Foundation, Australian Brewers’ Foundation, and the National Breast Cancer Foundation.

## The study participants

A total of 41,514 people were recruited: 24,469 women and 17,045 men. The study investigators decided to seek volunteers instead of random recruits, given that volunteers would be more likely to remain interested in the study.

The participants were aged between 27 and 80 years at recruitment with almost all between 40 and 69 years. Focusing on individuals 40 to 69 years of age allowed aspects of diet and other lifestyle habits to be examined in middle age and as the participants moved into late middle age and old age. In these databooks, results are grouped into the following age categories: <40 (n=213), 40–49 (n=12,994), 50–59 (n=13,518), 60–69 (n=14,704) and  $\geq 70$  (n=85).

All were originally from metropolitan Melbourne, although some participants have since moved interstate and overseas – and continue to be contacted for follow-up.

Most of the men and women recruited to the study were Australian-born, but close to one in three of all the people in the study were born outside Australia. They are migrants from Greece, Italy, Malta, England, Ireland, Scotland, Wales and New Zealand. In these databooks, they are grouped by region: Australia/New Zealand, Northern Europe and Southern Europe.

‘The outcomes of research have benefits for many of us. If no one participated there would be no

further development in research. Participating is very important for the future: with research the results would benefit those in need. A diet recommended by experts would benefit many.'

– a Health 2020 participant

## Why are one-quarter of study participants Southern European migrants?

The MCCA is one of the few multi-ethnic prospective studies of diet and lifestyle currently underway in the world and the only study of its kind in Australia.

About one-quarter of the people recruited are migrants from Southern Europe: especially Italy and Greece. This is one of the factors that make MCCA an exceptional study. We wanted to include a large proportion of people from Southern Europe so the study would include people with an extended range of dietary and possibly other factors. We also wanted to include a wider genetic variation in the sample than we would have found among only non-immigrant Melburnians.

When the MCCA began in 1989, there was some evidence that migrants from Southern Europe were less likely than their Australian-born counterparts to develop cancer or heart disease, had lower morbidity levels than people born in Australia, and lived on average four or five years longer. The MCCA was devised partly to test hypotheses about the role of the 'Mediterranean diet' in disease development.

The inclusion of people from Southern Europe also enables potentially valuable comparisons of factors such as obesity, alcohol use, cigarette smoking, physical activity, hypertension, diabetes, cholesterol, use of hormones in women and family history of cancer.

## How participants were recruited

Recruiting such a large number of people is by no means a quick or uncomplicated task. We were pleased to have the support of representatives of the Italian and Greek groups included in the study. These included the Vice-President of the Commission for Ethnic Affairs, the Assistant Director for Government and Community Liaison and Community Relations/Education, the coordinators of multicultural radio programs and journalists from the major multicultural papers.

The recruitment took four years, from 1990 to 1994. Many people were recruited through a letter of invitation, with details taken from the electoral rolls and phone books. We also used advertisements and announcements on multicultural radio and in newspapers, clubs and churches, to attract the interest of migrants who had not taken out citizenship and therefore would not be on the electoral rolls.

Another important way of recruiting people was to invite people who took part in the study to encourage friends and family to join.

The study also recruited using a mobile unit set up at major festivals, including the Lygon Street festival and the Aegean festival. Major manufacturing companies which employed a large number of migrants were contacted and asked if they would allow the unit to be located at the work premises for a time. Approaches were also made to have the unit placed in the centre of Melbourne, at the Bourke Street Mall.

## How interviewers were recruited and trained

Interviewers were employed as casual sessional employees and were trained and required to comply with guidelines in the MCCS Interviewers Manual. This manual included a code of ethics covering confidentiality, anonymity, non-communication of personal beliefs including religious beliefs, maintaining a professional manner and non-communication of medical advice. Interviewers were advised how to overcome barriers in cross-cultural communication, and required to stick to a defined interview process.

Interviewers' performance was monitored and evaluated.

## How the information was collected

Each participant was given a unique identifying code upon providing personal information at reception. (Appendix 1)

Participants were read a plain language statement describing the research and completed a consent form and a relative/friend contact form, to assist with follow-up in later years. The study was reviewed and approved before commencement by the Human Research Ethics Committee of the Cancer Council.

Face-to-face interviews were conducted with all participants. The interviews included:

- health and lifestyle questionnaire (see below)
- clinical data (see below)
- food frequency questionnaire (see below).

The questionnaires were rigorously reviewed in development to ensure that every question could

be justified. The researchers wished to keep the questionnaires as brief as possible, given that a long questionnaire would be arduous for participants. The same strenuous review applied to the selection of clinical measures.

The questionnaires as far as possible were interviewer administered and suitable for optical scanning.

Participants often found the interview process interesting and useful in itself and were pleased to receive a free check of their cholesterol and blood glucose, a blood pressure reading and a weight assessment.

*'We found the interview very beneficial and helpful in all aspects of health, diet and exercise. [For us] the diet is the most important aspect of the study.'*

**– a Health 2020 participant**

The computer system was a 386 machine with six computer terminals, a UNIX operating system and an INGRES database. Information was backed up daily from Monday to Friday and backups stored with the Cancer Council.

## What baseline measures were taken?

### **Health and lifestyle questionnaire**

All volunteers answered an interviewer-administered questionnaire that included questions on:

- personal medical history, including questions about asthma, angina, hypertension, diabetes, arthritis/rheumatism, cancer, kidney stones, gallstones, heart attack and stroke

- weight
- family history of heart disease, cancer, diabetes and stroke
- smoking
- alcohol
- physical activity: walking and vigorous exercise
- other details, including occupation, education, household size and social life.

Women in the study were asked about:

- menstrual history
- pregnancies
- breastfeeding
- use of the Pill and other hormones
- hysterectomy.

The health and lifestyle questionnaire, titled the 'Lifestyle Questionnaire' is included at Appendix 2.

### **Clinical data**

Clinical data were collected, including:

- blood pressure measurement
- blood sample
- measurements of standing height, weight (minus shoes and jackets), waist and hips circumference (over light clothes), bra size (for women), and lean and fat mass using bioelectric impedance.

This part of the study was administered by a nurse, who also took the drug and medical history described above.

### **Diet**

A third element of the data collection was the questions on eating habits and the food frequency questionnaire. There were 13 questions relating to dietary habits

including the types and frequency of fats and oils used, and the use of milk, sugar, garlic and diet supplements. The food frequency questionnaire was developed for the MCCS and was based on eight days of weighed food records from a large group of Australian, Italian and Greek-born people recruited for the pilot studies. People were then asked to report the frequency with which they ate foods from the categories:

- cereal foods, cakes and biscuits
- dairy foods and eggs
- meat, poultry, seafood and mixed dishes
- soups, salads and cooked vegetables
- fruit: dried, fresh, stewed and canned
- beverages and other food items.

The food frequency questionnaire, titled 'Health 2000 Answer Sheet: Eating Habits' is included at Appendix 3.

## **Why and how was blood collected?**

Nurses collected a sample of 15 ml of blood from each participant. Total plasma cholesterol and glucose were measured immediately. It was decided before the study began that participants would be informed if these tests showed elevated cholesterol or glucose levels and advised to see their doctor.

Samples of buffy coats and plasma have been stored in liquid nitrogen for future analyses of DNA and other substances of interest, such as hormones and markers of diet.

## How the information is being analysed

The main objective of the researchers is to see whether diet and other lifestyle factors affect the risk of disease.

Clinical material is being sampled for laboratory analysis using both the case-cohort and nested case-control approach. Statistical methods being used include logistic and cox regression to estimate associations.

## What diseases are being studied?

The MCCA is looking at the influence of diet and other lifestyle factors, including smoking, alcohol and exercise, on heart disease, stroke, type 2 diabetes (non-insulin-dependent), cancers of the colon, rectum, breast, prostate, stomach, lung and less common types of cancer, and premature death from all causes.

## What sorts of hypotheses are being tested?

The questionnaires and other measures will enable testing of hypotheses about the role of the following dietary factors in influencing disease development: vegetables, fruit, cereals and grains, meat, fish, alcohol, olive oil, fats, carotenoids, vitamin C, vitamin E, vitamin A, cholesterol, fibre, carbohydrates, fatty acids and energy.

People's smoking habits are also being recorded, along with information about such things as blood pressure, weight and waist measurement.

As participants in the study develop disease, their data will be compared with data from people unaffected by the disease.

## How are the outcomes being measured?

The MCCA researchers consult the Victorian Cancer Registry and death certificates issued in Victoria by the Registrar of Births, Deaths and Marriages, which are automatically sent to the cancer registry. As well, records are linked to the National Cancer Statistics Clearing House, which allows for the tracking of interstate movement of cancer cases, and the National Death Index.

Self-reported data have been collected for cardiovascular disease and type 2 diabetes and there are plans to do further linkages with other medical record databases.

Using these records is important should a participant die and information be required about their death. Contact is made with medical practitioners when health events of interest are reported in follow-up. At recruitment, participants were asked to give their consent to the investigators accessing medical records.

## How widely is the information being used?

It is hoped that this series of databooks will enable researchers nationally and internationally to access baseline MCCA data.

The MCCA data are available for use by the wider research community, following online submission to and approval by the MCCA Access Committee (Appendix 4) and ethics committee approval.

The MCCA is part of many international projects such as the Pooling Project of Prospective Studies of Diet and Cancer. This project pools and analyses the data from diet and cancer studies around the world, including the MCCA.

Participants in the study are kept informed of the progress of the study through regular newsletters.

## Protecting privacy

The MCCS conforms to strict privacy and confidentiality principles. Information is stored safely at The Cancer Council Victoria. Personal information, including individuals' names and addresses, does not appear on data used by researchers, who see only an ID number. Personal information will not be provided to anyone without a participant's written consent.

## Use of MCCS results to date

Scientific publications are the main outcome of the study. These include papers not only on cancer but also on nutrition, methodological issues, diabetes, cardiovascular disease, all-cause mortality, and so on.

Various analyses of data from the first 10 years of the MCCS study have been undertaken and published.

Major MCCS studies underway include:

- Risk factors for prostate cancer
- Dietary risk factors for colorectal cancer
- Risk factors for breast cancer
- Body size and composition, physical activity and colorectal cancer
- Risk factors for lymphohaematopoietic malignancy

- The predictors of type 2 diabetes in the MCCS
- Multiple imputation of missing data
- MCCS follow-up
- The predictors of healthy eating and physical activity in the MCCS
- Provision of dietary analysis to other researchers
- Development and evaluation of tools for dietary epidemiology.

One well-publicised result from the MCCS was the 2007 campaign launched in Victoria, the Obesity Campaign. Researcher Dr Robert MacInnis had examined the MCCS data and identified a link between waist measurement and some cancers, including:

- some cancers of the oesophagus
- cancer of the colon in men
- cancer of the breast in women
- cancer of the prostate (aggressive prostate cancers only).

Waist measurement was also a strong indicator of risk of myeloid leukaemia.

The results were considered significant enough for the Cancer Council to develop and promote a campaign urging people to check their waistlines and reduce their weight if the measurement was over 85 cm for women and 100 cm for men.

# Section II: About the databooks

## How to interpret the attributes of the variables

Variables have been numbered in the following manner:

A# – questions from H2000 Attendance (Appendix 1)

Q# – questions from the Lifestyle Questionnaire (Appendix 2)

M# – variables that were measured at baseline (eg weight or height)

X# – variables that have been derived from one or more variables

There are four data element types<sup>1</sup>:

1. Data element concept – a concept which can be represented in the form of a data element, described independently of any particular representation.
2. Data element - a unit of data for which the definition, identification, representation and permissible values are specified by means of a set of attributes.
3. Derived data element – a data element whose values are derived by calculation from the values of other data elements.
4. Composite data element – a data element whose values represent a grouping of the values of other data elements in a specified order.

## How to interpret the tables

Tables are presented for continuous and categorical variables. The tables for categorical variables present the number and percent of valid responses in each category. The tables for continuous variables contain n: the number of valid responses, missing: the number of missing responses, as well as the mean, standard deviation, the

following percentiles: 25th, 50th (median) and 75th, and the minimum and maximum values.

All tables are stratified by sex, country of birth and age at baseline.

## How to interpret the box plots

The box is drawn from the lower quartile to the upper quartile; its length gives the inter-quartile range. The horizontal line in the middle of the box represents the median. The 'whiskers' in this plot mark the upper and lower adjacent values of the data. The upper adjacent value is the value  $x_{(i)} \leq x_{(75)} + \frac{3}{2}(x_{(75)} - x_{(25)})$ .

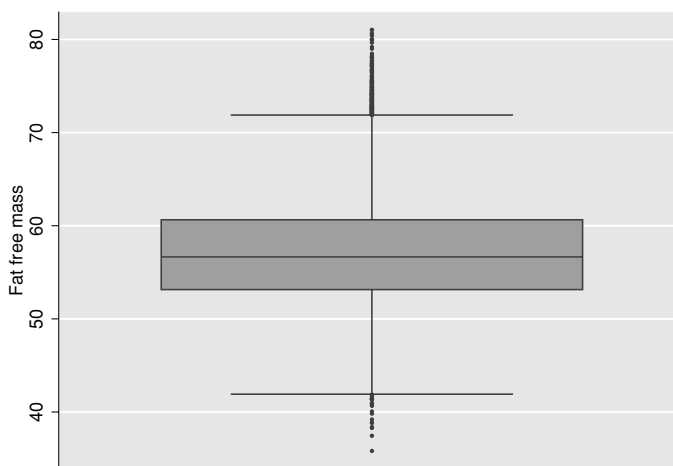
The lower adjacent value is the value  $x_{(i)}$

where  $x_{(i)} \geq x_{(25)} - \frac{3}{2}(x_{(75)} - x_{(25)})$ .  $x_{(25)}$  and  $x_{(75)}$

are the 25th and 75th percentiles. The dots outside of the 'whiskers' represent outliers, which are greater than the upper adjacent value or less than the lower adjacent value.

The box plots for this databook exclude extreme outliers (that is, values that are in the top 0.1 percentile).

Example:



Exclude values in the top 99.9 percentile

<sup>1</sup> Australian Institute of Health and Welfare 2001. *National Health Data Dictionary*. Version 10. AIHW Catalogue no. HWI 30. Canberra: Australian Institute of Health and Welfare.

# Section III:

## About this volume: clinical

The clinical data collection comprised:

- height
- weight
- waist circumference
- hip circumference
- lean and fat mass measured by bioelectric impedance
- blood pressure
- pulse
- blood samples for measuring blood glucose and cholesterol, and for storage to allow analysis of DNA and other substances of interest, such as hormones.

To measure height, participants were asked to remove shoes and outer clothing. They stood on a flat surface at a right angle to the vertical board of the stadiometer. Height was measured to the nearest millimetre.

For the measurement of weight, participants were asked to remove their shoes and any jumpers or jackets so that they wore only light indoor clothing. Electronic doctor's scales were used and weight measured to the nearest 0.1 kg.

Still in their light clothing, but with belts and restricting garments removed, waist and hip circumference were measured. A two-metre metal anthropometric tape was used. Participants were asked to stand with their weight evenly balanced on both feet and breathe normally. Measurements were taken on an out-breath. The waist measurement was taken at the narrowest part of the torso. The hip measurement was taken at the point of maximum circumference over the buttocks.

Body impedance (resistance/reactance) was measured using the RJL Systems BIA 101 body composition analyser. Participants lay on the examination bench with disposable electrodes attached to the right wrist and right ankle. A small current was passed through the body and resistance and reactance recorded. Several machines were used and validated against one another monthly to detect 'drift' in readings.

Blood pressure and pulse measurements were taken using a DINAMAP 1846SX automatic blood pressure monitor. Three measurements were taken, with the average of the latter two recorded.

Each participant gave 15 ml of blood. Blood was collected in vacutainers containing sodium heparin (for the analysis of lipids and for the extraction of plasma and lymphocytes for storage) and fluoride oxalate (for analysis of glucose). Vacutainers were labelled with the identifying bar code issued to each participant upon arrival. Total plasma cholesterol and glucose were measured immediately using Kodak Ektachem DT60 desktop analysers.

At least 2 x 1 ml samples of plasma were collected from every subject and placed in a central liquid nitrogen storage inventory. As well, blood was stored in buffy coat pellets, also stored in liquid nitrogen, or as dried whole blood clots on Guthrie papers. The cost of the buffy coat method was very high, so approximately ¼ of the participants had buffy coat pellets collected and the rest had their blood stored on Guthrie paper. Samples are stored at the Cancer Council and the University of Melbourne.

Please refer to the general introduction, titled '*About the MCCS*' for more information.

# Section IV: Clinical data results

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