Melbourne Collaborative Cohort Study

Cancer Epidemiology and Intelligence Division

Cancer Council Victoria

Data Request Form

# Section A – Request Details

Please complete the fields below:

|  |  |
| --- | --- |
| **Name:** |  |
| **Institution:** |  |
| **Department:** |  |
| **Position/Title:** |  |
| **Email Address:** |  |
| **Phone Number:** |  |
| **Study/Project Name:** |  |
| **Title of Approved Expression of Interest:** |  |
| **Approving Ethics Body:***Please attach evidence of study/project ethics approval* |  |
| **Requested Data Formats:** |  |
| **Date Submitted:** |  |
| **Date Required By:** |  |

Please return this completed form to the PEDIGREE coordinator via email: pedigree@cancervic.org.au

Data will be delivered to you securely via ShareFile unless otherwise requested. ShareFile login details will be provided to the email address you supplied above.

# Section B – Additional Details

Please specify any inclusion/exclusion criteria to be applied for your request:

|  |
| --- |
|  |

Please provide any other information which may assist us in processing your request:

|  |
| --- |
|  |

### MCCS Data Collection Periods

#### 1990-1994 – Baseline (*N* = 41,513)

Baseline collection included physical measurements, interviewer-administered questionnaire for lifestyle and health event information, self-administered dietary questionnaire, and blood collection.

#### 1995-1998 – Follow-Up 1 (*N* = 36,335)

Collection for the first wave of active follow-up (follow-up 1) included either a self-administered questionnaire or a telephone interviewer-administered questionnaire. For some participants with limited time, a ‘short’ version of the telephone questionnaire was administered.

#### 2003-2007 – Follow-Up 2 (*N* = 28,240)

Collections for the second wave of active follow-up (follow-up 2) included physical measurements, interviewer-administered or self-administered questionnaire for lifestyle and health event information, self-administered dietary questionnaire, and blood collection.

# Section C – Data

## Basic Variables

Every data set will include:

* Sex
* Country of birth
* Year/month of birth
* Attendance dates for requested data collection periods
* Type/version of questionnaires completed
* Type of clinics attended
* Date of death
* Date left Australia

Victorian deaths are updated 2-4 times a year through linkage with the Victorian Registry of Births, Deaths and Marriages. Victorian deaths can be released for all requests.

Interstate deaths are updated every year from linkage with the National Death Index (NDI). Data from NDI linkages can only be released with appropriate approval from the Australian Institute of Health and Welfare (AIHW). Please let us know if you would like to discuss the option of obtaining AIHW approval.

## Questionnaire and Physical Measurement Data[[1]](#footnote-1)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Group** | **Subgroup** | **Baseline** | **Follow-Up 1** | **Follow-Up 2** |
| **Demographic** | Employment Status | n/a |[ ]  n/a |
|  | Socioeconomic Status |[ ]  n/a |[ ]
|  | Marital Status |[ ]  n/a | n/a |
|  | Handedness | n/a |[ ]  n/a |
| **Clinical[[2]](#footnote-2)** | Height |[ ]  n/a | n/a |
|  | Weight |[ ] [ ] [ ]
|  | BMI |[ ]  n/a |[ ]
|  | Hip |[ ]  n/a |[ ]
|  | Waist |[ ] [ ] [ ]
|  | Blood Pressure/Pulse |[ ]  n/a |[ ]
|  | Bioimpedance Measures |[ ]  n/a |[ ]
| **Alcohol** | Drinking Status |[ ]  n/a | n/a |
|  | Recent Consumption[[3]](#footnote-3) |[ ] [ ] [ ]
|  | Lifetime Consumption[[4]](#footnote-4) |[ ]  n/a | n/a |
|  | Alcohol Nutrient Intakes | n/a | n/a |[ ]
| **Diet** | Mediterranean Diet Score |[ ]  n/a |[ ]
|  | Alternative Healthy Eating Index |[ ]  n/a | n/a |
|  | Dietary Inflammatory Index |[ ]  n/a | n/a |
|  | Food/Beverage Frequencies |[ ] [ ] [ ]
|  | Food/Beverage Intakes (Grams/Day)[[5]](#footnote-5) | n/a | n/a |[ ]
|  | Food/Beverage Nutrient Intakes[[6]](#footnote-6) |[ ]  n/a | [ ]  |
| **Smoking** | Cigarettes |[ ] [ ] [ ]
|  | Pipes/Cigars |[ ]  n/a | n/a |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Group** | **Subgroup** | **Baseline** | **Follow-Up 1** | **Follow-Up 2** |
| **Health Conditions[[7]](#footnote-7)** | Acne | n/a | n/a |[ ]
|  | Allergies (Food/Drug) | n/a | n/a |[ ]
|  | Angina |[ ] [ ] [ ]
|  | Angioplasty | n/a |[ ] [ ]
|  | Arthritis |[ ]  n/a |[ ]
|  | Asthma |[ ] [ ] [ ]
|  | Barrett’s Oesophagus | n/a | n/a |[ ]
|  | Cancer[[8]](#footnote-8) |[ ] [ ]  n/a |
|  | Cataracts | n/a |[ ]  n/a |
|  | Diabetes |[ ] [ ] [ ]
|  | Eczema | n/a | n/a |[ ]
|  | Fractures/Broken Bones | n/a |[ ] [ ]
|  | Gallstones |[ ] [ ]  n/a |
|  | Hay Fever | n/a | n/a |[ ]
|  | Heart Attack |[ ] [ ] [ ]
|  | Heart Bypass | n/a |[ ] [ ]
|  | Heart Failure | n/a |[ ]  n/a |
|  | Heartburn/Reflux | n/a | n/a |[ ]
|  | High Cholesterol | n/a |[ ]  n/a |
|  | Hip/Knee Replacements | n/a | n/a |[ ]
|  | Hives | n/a | n/a |[ ]
|  | Hypertension |[ ] [ ]  n/a |
|  | Kidney Stones |[ ] [ ]  n/a |
|  | Liver Disease | n/a |[ ]  n/a |
|  | Stroke |[ ] [ ] [ ]
|  | Weight Fluctuations |[ ]  n/a | n/a |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Group** | **Subgroup** | **Baseline** | **Follow-Up 1** | **Follow-Up 2** |
| **Medications** | Drug Name/Class[[9]](#footnote-9) |[ ]  n/a | n/a |
|  | Aspirin | n/a |[ ]  n/a |
|  | NSAIDs | n/a |[ ]  n/a |
|  | Paracetamol | n/a |[ ]  n/a |
|  | Heartburn/Reflux Medications | n/a | n/a |[ ]
| **Medical Examinations** | Barium Enema | n/a |[ ]  n/a |
|  | Barium Meal | n/a |[ ]  n/a |
|  | Breast Exam | n/a |[ ]  n/a |
|  | CAT/MRI Scan | n/a |[ ]  n/a |
|  | Chest X-Ray | n/a |[ ]  n/a |
|  | Colonoscopy | n/a |[ ] [ ]
|  | Faecal Occult Blood Test | n/a |[ ] [ ]
|  | Gastroscopy | n/a | n/a |[ ]
|  | Mammogram | n/a |[ ] [ ]
|  | PAP Smear | n/a |[ ]  n/a |
|  | PSA Test | n/a |[ ] [ ]
|  | Rectal Exam | n/a |[ ]  n/a |
|  | Sigmoidoscopy | n/a |[ ] [ ]
|  | Skin Exam | n/a |[ ]  n/a |
|  | Vaginal Exam | n/a |[ ]  n/a |
| **Physical Activity** | Physical Activity Score[[10]](#footnote-10) |[ ]  n/a |[ ]
|  | Activity Frequencies[[11]](#footnote-11) |[ ] [ ] [ ]
| **Health and Wellbeing** | SF-12 Health Survey[[12]](#footnote-12) | n/a | n/a |[ ]
|  | Physical/Emotional State[[13]](#footnote-13) | n/a |[ ]  n/a |
|  | Activities of Daily Living[[14]](#footnote-14) | n/a | n/a |[ ]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Group** | **Subgroup** | **Baseline** | **Follow-Up 1** | **Follow-Up 2** |
| **Social and Psychological** | Educational Level |[ ]  n/a | n/a |
|  | Feelings/Emotions |[ ]  n/a |[ ]
|  | Reactions to Anger |[ ]  n/a | n/a |
|  | Family/Friend Visits |[ ] [ ] [ ]
|  | Social Activity Time |[ ]  n/a |[ ]
|  | Number in Household |[ ] [ ] [ ]
|  | Living Arrangements | n/a | n/a |[ ]
|  | Pet Ownership | n/a | n/a |[ ]
| **Men[[15]](#footnote-15)** | Enlarged Prostate | n/a |[ ] [ ]
|  | Male Hair Thickness | n/a | n/a |[ ]
|  | Offspring | n/a |[ ]  n/a |
|  | Urination | n/a |[ ] [ ]
|  | Vasectomy | n/a |[ ]  n/a |
| **Women[[16]](#footnote-16)** | Bra/Cup Size |[ ]  n/a | n/a |
|  | Contraceptive Pill |[ ] [ ] [ ]
|  | Female Hair Thickness | n/a | n/a |[ ]
|  | Hormone Replacement Therapy |[ ] [ ] [ ]
|  | Alternatives to HRT | n/a | n/a |[ ]
|  | Hysterectomy/Oophorectomy |[ ] [ ] [ ]
|  | Menarche |[ ]  n/a | n/a |
|  | Menopause |[ ] [ ] [ ]
|  | Pregnancy |[ ] [ ]  n/a |
|  | Lactation |[ ]  n/a | n/a |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Group** | **Subgroup** | **Baseline** | **Follow-Up 1** | **Follow-Up 2** |
| **Family Members[[17]](#footnote-17)** | Adopted Status | n/a | n/a |[ ]
|  | Twin Status |[ ]  n/a | n/a |
|  | Age and Vital Status of Parents |[ ]  n/a | n/a |
|  | Number of Siblings |[ ]  n/a |[ ]
|  | Number of Children |[ ]  n/a | n/a |
|  | Familial Cancer |[ ]  n/a | n/a |
|  | Familial Bowel Cancer | n/a | n/a |[ ]
|  | Familial Breast Cancer[[18]](#footnote-18) | n/a |[ ] [ ]
|  | Familial Prostate Cancer[[19]](#footnote-19) | n/a |[ ] [ ]
|  | Familial Diabetes |[ ]  n/a | n/a |
|  | Familial Heart Attack |[ ]  n/a |[ ]
|  | Familial Stroke |[ ]  n/a |[ ]

## Blood and Urine Lab Test Results

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Study** | **Results** | **Baseline** | **Follow-Up 1** | **Follow-Up 2** | **Other** |
| **Entire Cohort** | Glucose |[ ]  n/a |[ ]  n/a |
|  | Cholesterol |[ ]  n/a |[ ]  n/a |
|  | Triglycerides | n/a | n/a |[ ]  n/a |
| **Case-Cohort (2000-2004)** | Carotenoids |[ ]  n/a | n/a | n/a |
|  | Fatty Acids |[ ]  n/a | n/a | n/a |
|  | Hormones |[ ]  n/a | n/a | n/a |
|  | Insulin |[ ]  n/a | n/a | n/a |
|  | Triglycerides (Case-Cohort) |[ ]  n/a | n/a | n/a |
|  | Homocysteine |[ ]  n/a | n/a | n/a |
|  | HDL Cholesterol |[ ]  n/a | n/a | n/a |
|  | C-Reactive Protein[[20]](#footnote-20) |[ ]  n/a | n/a | n/a |
|  | NMR-Determined Lipoproteins20 |[ ]  n/a | n/a | n/a |
| **Vitamin D Case-Cohort** | Vitamin D |[ ]  n/a | n/a | n/a |
| **Nested Case-Control Studies** | B Vitamins[[21]](#footnote-21) |[ ]  n/a | n/a | n/a |
| **Dietary Calibration Study** | Urine Electrolytes[[22]](#footnote-22) | n/a | n/a | n/a |[ ]

### Sub-Study Descriptions

#### The Case-Cohort Study (2000-2004)

The case-cohort design was used to study the association of biomarkers in plasma and the risk of breast, prostate, and colorectal cancer, cardiovascular death, and diabetes. All the cases were included in the case-cohort if they had been identified as having the outcome of interest by 30 June 2002, together with a random sample of all participants in the MCCS, called the sub-cohort. A series of plasma biomarkers were measured in cases and in the sub-cohort. Fatty acids and hormones were measured in all case-cohort subgroups; insulin, high-density lipoproteins, total cholesterol, and triglycerides were measured in the cardiovascular death and diabetes subgroups only.

#### Vitamin D Case-Cohort Study

A case-cohort sub-study (*N* = 7,045) was used to study the association between baseline blood concentrations of vitamin D and subsequent death from any cause and occurrence of breast, prostate, and colorectal cancer, and type 2 diabetes. Vitamin D concentrations were measured from dried blood spots.

#### Nested Case-Control Studies

Blood and urine lab test results are available for some nested case-control studies. B vitamins were measured in plasma for the kidney cancer, lung cancer, and urothelial cell carcinoma nested case-control studies.

#### Dietary Calibration Study

Sub-study of 900 participants randomly selected at follow-up 2, covering six subgroups defined by sex and country of birth (Australia, Greece, and Italy). The study was used to evaluate the reliability and validity of the food frequency questionnaires administered to participants in the follow-up of the MCCS and to provide calibration coefficients. Urine samples were collected shortly after follow-up 2 in 2007 and 2008.

## Cancer Data

|  |  |  |
| --- | --- | --- |
| **Group** | **Requested** | **Details** |
| Tumour Details |[ ]   |
| Breast Cancer Treatment and Outcome Data |[ ]   |
| Breast Cancer Immunohistochemistry |[ ]   |
| Colorectal Cancer Immunohistochemistry |[ ]   |

### Cancer Data Details

#### Cancer Data

MCCS participants are regularly matched to the Victorian Cancer Registry (VCR) identifying cancers registered since compulsory notification in 1982 with some earlier notifications included as reported to VCR. Linkage to VCR and extraction of cancer cases is done at least once a year. These data can be released for all data requests.

Interstate cancer diagnoses are updated every year via linkage with the Australian Cancer Database (ACD). Data from ACD linkages can only be released with appropriate approval from the Australian Institute of Health and Welfare (AIHW). Please let us know if you are interested in obtaining AIHW approval.

#### Breast Cancer Treatment Data

Treatment data was collected for all post-baseline MCCS breast cancer participants diagnosed prior to June 2010 (only one tumour per participant). Treatment variables included surgery, chemotherapy, radiotherapy, endocrine therapy, and Herceptin.

#### Breast Cancer Immunohistochemistry

Immunohistochemistry data for breast cancer cases diagnosed prior to 31 December 2009.

#### Colorectal Cancer Immunohistochemistry

Colorectal cancer IHC for cases diagnosed prior to 2009 (including MMR, MSI, mutation of oncogenes, CIMP, PIK3CA mutation, pathology review).

## Other Data

|  |  |  |
| --- | --- | --- |
| **Group** | **Requested** | **Details** |
| Causes of Death |[ ]   |
| Genetic/SNP Data |[ ]   |
| Methylation Data |[ ]   |
| Mammographic Density |[ ]   |
| Retina Images |[ ]   |
| Taste Perception and Food Preferences |[ ]   |

### Other Data Details

#### Causes of Death

The causes of death for Victorian deaths are obtained from VCR (Victorian Cancer Registry) if cancer is the cause of death. Victorian non-cancer causes of death are only obtained from the NDI (National Death Index). NDI also provides cancer cause of death for Victorian deaths.

The causes of death for interstate deaths are obtained only from NDI.

Causes of death from VCR (death registered in Victoria and cancer-related) are updated at least once a year and can be released for all data requests. Causes of death from NDI (both interstate and Victorian deaths) are updated every year and can only be released with appropriate approval from the Australian Institute of Health and Welfare (AIHW). Please let us know if you would like to discuss the option of obtaining AIHW approval.

#### Genetic/SNP Data

Genotyping has been conducted on germline DNA samples from a subset of MCCS participants using the Illumina OncoArray BeadChip. This subset includes all incident cases of breast, prostate, colorectal cancer, and urothelial cell carcinoma, diagnosed before 2013, and controls matched to a subset of these using incidence density sampling. OncoArray contains more than 500,000 genetic variants, including a 250K GWAS backbone.

#### Methylation Data

DNA methylation has been determined in peripheral blood DNA samples collected at baseline from participants in eight nested case-control studies using the Illumina HumanMethylation450 BeadChip array. These include approximately 3,000 breast, prostate, colorectal, lung, gastric and kidney cancer, urothelial cell carcinoma, or mature B-cell neoplasm case-control pairs. DNA methylation has also been measured in peripheral blood DNA samples collected at follow-up 2 for a subset of 1,100 controls from these studies.

#### Mammographic Density

Dense area and total breast area has been determined using *Cumulus* for a subset of female breast cancer cases diagnosed before 2008 and, for each, four matched controls, all from the mammogram closest to baseline, as identified by record linkage to BreastScreen Victoria in 2009.

#### Retina Images

At follow-up 2, non-mydriatic retinal photography was performed by collaborators from the Centre for Eye Research Australia (CERA) to study age-related macular degeneration (AMD) and early markers of cardiovascular disease (CVD). A total of 22,405 follow-up 2 participants (80%) took part in this study, with digital retina images from 21,287 passing quality control.

#### Taste Perception and Food Preferences

Taste perception and food preferences measured in 2016 for 494 participants who were born in Australia, under the age of 77 years at 31 December 2014, and with no previous diagnosis of cancer. A commercially available taste test kit was administered.

1. Amount/type of data may vary between data collection periods. [↑](#footnote-ref-1)
2. Follow-up 1 data for this section is self-reported only. [↑](#footnote-ref-2)
3. Baseline data includes consumption in the previous week and by decade of age; Follow-up 1 and Follow-up 2 both include consumption in the previous year. [↑](#footnote-ref-3)
4. Includes recalled alcohol consumption for each decade of age and average intake over lifetime. [↑](#footnote-ref-4)
5. Derived from the Food Frequency Questionnaire data. [↑](#footnote-ref-5)
6. Baseline: includes alcohol intakes; Follow-up 2: alcohol nutrient intakes available separately and may need to be combined in most cases. [↑](#footnote-ref-6)
7. Self-reported health conditions. [↑](#footnote-ref-7)
8. Self-reported cancer data. Please see Section C4 for cancer linkage data if required. [↑](#footnote-ref-8)
9. Baseline medications classified using Medical Director (MD2) software. Follow-up 2 medications data may also be available on request (classified using WHO Drug Dictionary Enhance). [↑](#footnote-ref-9)
10. Metabolic Equivalent of Task (METs). [↑](#footnote-ref-10)
11. Baseline activities: walking, work, home, vigorous, non-vigorous; Follow-up 1 activities: walking, vigorous; Follow-up 2 activities: walking, work, home, leisure, sitting, television viewing hours. [↑](#footnote-ref-11)
12. Includes twelve questions relating to physical health and emotional problems, plus derived New England Medical Center (NEMC) T-scores. [↑](#footnote-ref-12)
13. Includes a subset of SF-12 questions. [↑](#footnote-ref-13)
14. Includes questions about difficulty with daily activities (e.g. bathing, dressing, eating, etc.). [↑](#footnote-ref-14)
15. See 'Medical Examinations' section for PSA test. [↑](#footnote-ref-15)
16. See 'Medical Examinations' section for female-specific examinations. [↑](#footnote-ref-16)
17. Familial data includes first-degree relatives (unless otherwise specified). Self-reported data only. [↑](#footnote-ref-17)
18. Follow-up 1 data is only available for female participants and includes grandmothers/aunts. [↑](#footnote-ref-18)
19. Follow-up 1 data is only available for male participants and includes grandfathers/uncles. [↑](#footnote-ref-19)
20. Measured for the cardiovascular death subgroup only. [↑](#footnote-ref-20)
21. Data is available for the kidney cancer nested case-control study. Data may also be available on request for the urothelial cell carcinoma and lung cancer nested case-control studies. [↑](#footnote-ref-21)
22. Includes: potassium, urea, creatinine, magnesium, sodium, and protein concentration results. [↑](#footnote-ref-22)