

## UK Women's Cohort Study [UKWCS]

### GENERAL INFORMATION

**Name** UK Women's Cohort Study  
**Acronym** UKWCS  
**Last update** 09/11/2013

#### Affiliation

#### Principal investigators

Janet Cade (Professor) University of Leeds  
 Victoria Burley (Project Manager, Dr.) University of Leeds  
 Darren Greenwood (statistician) University of Leeds

#### Contacts

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 Victoria Burley (Principal Investigator) University of Leeds  
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 Email: [v.j.burley@leeds.ac.uk](mailto:v.j.burley@leeds.ac.uk)

#### Website

<http://www.leeds.ac.uk/medicine/ceb/NutEp/ukwcs/index.htm>

#### Funding agency

|                            | Percentage | Category |
|----------------------------|------------|----------|
| World Cancer Research Fund | --         | Charity  |

### OBJECTIVES

To study diet in relation to long-term health outcomes.

#### Research Focus

- ✗ Broad approach with no specific target of interest (study built as an infrastructure for a broad range of unspecified scientific activities/questions).
- ✓ Target specific questions of interest (predefined scientific targets like, cardiovascular diseases, social environment, specific health trajectories etc.)

#### Topics

#### ICD-10 classification

- ✓ Neoplasms (C00-D48)
- ✓ Diseases of the circulatory system (I00-I99)

### METHODS

Legend ✓ Yes ✗ No ? Unknown

#### General design

**Study design** Cohort  
**Type of participants** Individuals  
**Target or final number of participants** 35000  
**Target or final number of DNA** 7000

#### Participant selection / Characteristics of the population

##### Selection criteria

- ✓ Gender Women
- ✓ Age Minimum: 35 years Maximum: 69 years
- ✓ Country of residence United Kingdom (*England, Wales, Scotland*)
- ✓ Other criteria Emphasis was put on recruiting similar, large numbers of vegetarians, fish-eaters and meat-eaters.

#### Data Sources

**Cross-sectional** **Longitudinal follow-up**



- ✓ Questionnaires to participants/respondents      x      x
- ✓ Biological samples      x      x

**Sample management**

**Biological samples**

- ✓ Blood      ✓ Buccal cells
- ? Cord blood      ? Tissues
- ? Saliva      ? Urine

**Genome-Wide Association (GWA) analyses**

- x No genome-wide association analysis

**GOVERNANCE**

Legend ✓ Yes x No

**Allow access to data or samples to external researchers**

- ✓ Data (questionnaire-derived, measured...)
- ✓ Biological samples
- ✓ Other (Access to data is provided or foreseen with appropriate agreements.)

**STATUS**

**Current status**

| Phase  | Start | End  |
|--|-------|------|
| Preparation phase/Pilot                        | --    | --   |
| Baseline recruitment / initial data collection | 1995  | 2002 |
| Follow-up of participants                      | 1995  | --   |

**Current number of participants recruited**      35372 in date of 01/01/2010

**Current number of collected DNA samples**      7932 in date of 01/01/2010

DNA is available from blood and cheek cells for a subset of subjects who were involved in a study of iron storage genotype (5343 cheek cell DNA; 2589 from blood samples).



## Questionnaire

### The UK Women's Nutrition & Lifestyle Survey

This Catalogue was archived on: 2013-12-09. Information included in this Catalogue is for informational purposes only.

#### General Information

|                                   |   |
|-----------------------------------|---|
| <b>Name</b>                       | The UK Women's Nutrition & Lifestyle Survey                     |
| <b>Last update</b>                | 04/02/2009  |
| <b>Version or reference year</b>  | Green   |
| <b>Phase</b>                      | Baseline  |
| <b>Year interval</b>              | 1995 to 1998  |
| <b>Supplementary informations</b> | Purple phase 2 questionnaire also available for second contact. |

#### Questionnaire owner

University of Leeds

#### Contacts

|  |   |
|--|---|
| Victoria Burley (Project Manager, Dr.) | University of Leeds<br>Leeds LS2 9JT<br>Phone: 0113 343 6946<br>Email: <a href="mailto:v.j.burley@leeds.ac.uk">v.j.burley@leeds.ac.uk</a> |
| Janet Cade (Professor)                 | University of Leeds<br>Leeds LS2 9JT<br>Phone: 0113 343 6946<br>Email: <a href="mailto:j.e.cade@leeds.ac.uk">j.e.cade@leeds.ac.uk</a>     |

#### Utilization conditions

Contact should be made with the UKWCS team for guidance.

#### Information on validity

Some information on validity of questionnaire can be found at: Spence M, Cade JE, Burley VJ, Greenwood DC. 'Ability of the UK Women's Cohort Food Frequency Questionnaire to rank dietary intakes: a preliminary validation study'. Proc Nut Soc 2002;61;117A

#### References

Cade, J.E.; Burley, V.J.; Greenwood, D.C. and the UK Women's Cohort Study Steering Group. Dietary fibre and risk of breast cancer in the UK Women's Cohort Study. International Journal of Epidemiology. 2007, 36: 431 - 438.

Spence M, Cade JE, Burley VJ, Greenwood DC. 'Ability of the UK Women's Cohort Food Frequency Questionnaire to rank dietary intakes: a preliminary validation study'. Proc Nut Soc 2002;61;117A.

Cade JE, Burley VJ, Greenwood DC and the UK Women's Cohort Study Steering group. 'The UK Women's Cohort Study: comparison of vegetarians, fish eaters and meat eaters.' Public Health Nutrition 2004;7;871-878.

Taylor, E.F.; Burley, V.J.; Greenwood, D.C.; Cade, J.E. Meat consumption and risk of breast cancer in the UK Women's Cohort Study. British Journal of Cancer. 2007, 96, 1139 – 1146.

#### Methods

Legend  Yes  No

#### Respondent

- Participant
- Proxy

#### Administration environment

- Over the phone
- Hospital, clinic, university or recruitment center
- Respondent / Proxy residence

#### Administration format

- Paper questionnaire
- Computerized
- Other (FFQ section is computerised in addition to paper version)

#### Administration language

English

#### Documents

##### Available Format

- [Adapted questionnaire](#) 

- [UKWC\\_questionnaire\\_baseline](#)

**NOTICE:** HTML document format may differ slightly from the actual questionnaire. Please refer to the original PDF document for exact reproduction.

## General Information

|                                  |   |
|----------------------------------|---|
| <b>Name</b>                      | The UK Women's Nutrition & Lifestyle Survey |
| <b>Number of Question Blocks</b> | 53  |

## Questionnaire and Question Block List

Click on the to see the block of questions related to a domain or a group of domains.

### Block 1

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Cereals, Bread, Starches
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Sweets, Baked goods

### Block 2

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Milk products
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Fat Intake

### Block 3

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Fat Intake

### Block 4

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Sweets, Baked goods

### Block 5

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Beverages (other than water or alcohol)
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Fat Intake
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Milk products
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Vegetables and Fruits

### Block 7

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Cereals, Bread, Starches

### Block 8

- Life Habits/Behaviours / Nutrition / Food intake and Frequency

### Block 9

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Sweets, Baked goods
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Meat, Eggs, Fish and Alternatives

### Block 10

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Vegetables and Fruits

### Block 11

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Meat, Eggs, Fish and Alternatives

### Block 12

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Vegetables and Fruits

### Block 13

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Vegetables and Fruits
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Fat Intake
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Sweets, Baked goods

### Block 14

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Caffeine
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Beverages (other than water or alcohol)

### Block 15

- Life Habits/Behaviours / Alcohol use

### Block 16

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Vegetables and Fruits
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Sweets, Baked goods

### Block 17

- Life Habits/Behaviours / Nutrition / Nutritional Behaviours and Perception of Nutritional Habits

### Block 18

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Cereals, Bread, Starches
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Vegetables and Fruits

### Block 20

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Vegetables and Fruits

**Block 24**

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Meat, Eggs, Fish and Alternatives

**Block 26**

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Beverages (other than water or alcohol)
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Milk products
- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Fat Intake

**Block 27**

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Cereals, Bread, Starches

**Block 28**

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Salt and Food Supplement

**Block 29**

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Cereals, Bread, Starches

**Block 30**

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Fat Intake

**Block 31**

- Life Habits/Behaviours / Nutrition / Food intake and Frequency / Salt and Food Supplement
- Health Information / Medication Intake (ATC/DDD) / Various

**Block 32**

- Life Habits/Behaviours / Nutrition / Nutritional Behaviours and Perception of Nutritional Habits

**Block 34**

- Life Habits/Behaviours / Alcohol use

**Block 35**

- Life Habits/Behaviours / Tobacco use

**Block 36**

- Health Information / Participants Early Life Conditions / Participant's Birth weight

**Block 37**

- Body structures / Anthropometric structures / Anthropometric measures / Weight

**Block 38**

- Body structures / Anthropometric structures

**Block 39**

- Body structures / Anthropometric structures / Anthropometric measures / Height

**Block 40**

- Body structures / Anthropometric structures

**Block 41**

- Life Habits/Behaviours / Physical activity / Activities/Exercise and Frequency

**Block 42**

- Health Information / Individual Disease history / Endocrine, nutritional and metabolic diseases
- Health Information / Individual Disease history / Diseases of the circulatory system
- Health Information / Individual Disease history / Diseases of the digestive system
- Health Information / Individual Disease history
- Health Information / Individual Disease history / Neoplasms
- Health Information / Medical Health Intervention (C239)

**Block 43**

- Health Information / Medical Health Intervention (C239) / Physical/Physiological Therapeutic Interventions
- Health Information / Medication Intake (ATC/DDD)

**Block 44**

- Health Information / Familial Disease History (ICD10\*) / Diseases of the circulatory system
- Health Information / Familial Disease History (ICD10\*) / Neoplasms

**Block 45**

- Socioeconomic Characteristics / Education level / Subject education level

**Block 46**

- Socioeconomic Characteristics / Working status / Subject Working status/history

**Block 47**


- Sociodemographic Characteristics / Household Status / Subject Household Status

**Block 48**


- Socioeconomic Characteristics / Working status / Subject's partner working status/history

**Block 49** 

- Sociodemographic Characteristics / Ethnicity/Race

**Block 50** 


- Health Information / Women's health / Menstruation

**Block 51** 


- Health Information / Reproductive history
- Health Information / Reproductive history / Parity/Gravidity

**Block 52** 

- Health Information / Reproductive history / Number of children

**Block 53** 


- Health Information / Women's health / Breast feeding

**Block 54** 

- Health Information / Individual Disease history / Diseases of the genitourinary system

**Block 55** 


- Health Information / Medication Intake (ATC/DDD) / Genito urinary system and sex hormones (G)

**Block 56** 

- Health Information / Women's health / Menstruation

**Block 57** 

- Health Information / Medication Intake (ATC/DDD) / Genito urinary system and sex hormones (G)
- Health Information / Women's health / Menopause

**Block 58** 

- Health Information / Medical Health Intervention (C239) / Physical/Physiological Therapeutic Interventions / Therapeutic Interventions on the Genitourinary System

**Block 59** 

- Health Information / Medical Health Intervention (C239) / Diagnostic Interventions / Diagnostic Interventions on the Skin, Subcutaneous Tissue, and Breast

**Block 60** 

- Sociodemographic Characteristics / Age/Birth Date / Subject age / birth date

## Access

### GENERAL INFORMATION

**Study name** UK Women's Cohort Study [UKWCS]  
**Last update** 01/31/2012

#### Contacts

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### ACCESS

Legend ✓ Yes ✗ No

**Data or samples can be accessed by researchers outside the study/biobank (i.e. a researcher who is not an internal researcher of the study/biobank with research privileges)**

- ✓ Access to at least part of the collected **data** is available for researchers outside the study
- ✓ Access to at least part of the collected **samples** is available for researchers outside the study

**Data/samples can leave the study/biobank facility/country under the policies and regulations of your study**

#### Data

- ✓ Can leave study/biobank facility
- ✓ Can leave the country

#### Samples

- ✓ Can leave study/biobank facility
- ✓ Can leave the country

? Participants can not be contacted for additional information or sampling

**Restriction to the category/type of investigator requesting access to your study**

There are no restriction related to the categories of investigators requesting access

**Limitations regarding the scientific scope of the projects that can use the study's data/samples**

- ✓ Scope of the projects using the data of the study is limited (Additional ethical approval may be required depending on the nature of the project.)
- ✓ Scope of the projects using the samples of the study is limited (Additional ethical approval may be required depending on the nature of the project.)

### ADDITIONAL INFORMATIONS

Legend ✓ Yes ✗ No

**Approval process leading to access**

To grant access, the study requires approval/authorization/documents by the following entities of the applicant's institution

- ✗ Ethics committee of applicant's institution (or another organization having jurisdiction or required by local governance rules)
- ✗ Scientific committee of applicant's institution (or another organization having jurisdiction or required by local governance rules)
- ? Others

To grant access, the study requires approval/authorization/documents by the following entities of the study

- ✗ Ethics committee having jurisdiction over the study/biobank
- ✗ Scientific committee having jurisdiction over the study/biobank
- ? Another local committee/organization relevant to the study

**Information regarding fees to access data/samples**

#### Data

- ✗ There are fixed fees to access data
- ✓ There are scalable costs to access data varying according to the investigator (e.g. national investigators, students, public/private institutions, etc.)

#### Samples



- ✘ There are fixed fees to access samples
- ✔ There are scalable fees to access samples varying according to the investigator (e.g. national investigators, students, public/private institutions, etc.)

**To protect confidentiality, access will be provided in the following format**

- ✘ Samples are anonymized (irreversible½destruction of the identity of the participant)
- ✘ Data is anonymised (irreversible½destruction of the identity of the participant)
- ✘ Samples are coded (identification by a code(s), with possible½reversible½process to identify the participant)
- ✔ Data are coded (identification by a code(s), with possible½reversible½process to identify the participant)

**Additional information**

Encryption would be expected.

**Investigators will be have to**

- ✘ Submit their publications (articles, presentation, etc) to the study for review prior to public disclosure
- ✘ Periodically report to the study on the uses of data/samples and/or publications made possible thanks to the use of this research material
- ✘ Recognize the study as a co-author on their publication
- ✘ Acknowledge the study in their publication (either in the text or in the footnotes)
- ✔ Others (Inclusion of study team member on relevant publications. Also, intellectual property rights resulting from the research using data/samples have to be negotiated with study representative. Lastly, return of results/data back to the study (e.g. GWAS, biochemical tests, etc.)

**Study in-house analysis services**

|  | Offered | Mandatory |
|--|---------|-----------|
| In-house laboratory analysis for applicants  | ✘       | ✘         |
| In-house statistical analysis for applicants | ✔       | ✘         |





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Website: <http://www.p3gobservatory.org>

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