

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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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

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

Questionnaire owner

University of Leeds

Contacts

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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

Name	The UK Women's Nutrition & Lifestyle Survey
Number of Question Blocks	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 (irreversible destruction of the identity of the participant)
- ✘ Data is anonymised (irreversible destruction of the identity of the participant)
- ✘ Samples are coded (identification by a code(s), with possible reversible process to identify the participant)
- ✔ Data are coded (identification by a code(s), with possible reversible process to identify the participant)

Additional information

Encryption would be expected.

Investigators will 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	✔	✘



Generated on: 09/22/2017
Website: <http://www.p3gobservatory.org>

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