General Information

1.1  Id number

1.2'  country
    Belgium (1); France (2); Germany (3); Italy (4); the Netherlands (5); United Kingdom (6); Spain (7); Slovakia (8)

1.3  case / control status
    control (0); case (1)

1.4  sex
    male (0); female (1); not known (6)

1.5  date of birth
    (dd-mm-yyyy) (not known: all 8)

1.6  ethnicity
    Caucasian (1); North African (2); other African (3); Asian (4); Afro-Caribbean (5); other (6); not known (8)

1.7  subject’s marital status
    single (1); married/cohabiting (2); divorced (3); widow (4); not known (8)

1.8  Is/ was subject right- or left-handed?
    righthanded (1); lefthanded (2); not known (8)

1.9  How many years of full time education did subject complete? (not known: all 8)

1.10 this question only for non-UK cases
    Has subject lived in or visited the United Kingdom during the period 1990-1996? lived for a period > 6 months (1); lived/visited for a period < 6 months (2); no (3); not known (8)

1.11  date of interview
    (dd-mm-yyyy) (not known: all 8)
1.12 place of interview
   hospital (1); home (2); phone (3); other (4); not known (8)

1.13 informant
   spouse (1); self (2); son/daughter (3); nephew/niece/cousin
   (4); sibling (5); parent (6); other (7); not known (8)
   How long has the informant known subject? (in years)

1.14 interviewer
   research physician (1); research assistant (2); treating
   physician (3); nurse (4); other (5); not known (6)

1.15 sequence of interview
   before discussion of possible CJD diagnosis with family (1);
   after discussion (2); not known (8)
2.1 Identification number of matched case

2.2 Origin of control
hospital control with neurologic disease (1); hospital control without neurologic disease (2); nursing home control with neurologic disease (3); nursing home control without neurologic disease (4); GP control (5)

2.3 Controls matched for

- hospital: no (0); yes (1); not known (8)
- age
- sex: male (0); female (1); not known (8)
- residence: no (0); yes (1); not known (8)

2.4 Number of controls refused for matched case
(not known: 89)
3.1 source
neurologist (1); psychiatrist (2); (neuro)pathologist (3); death certificate (4); general practitioner (5); EEG department (6); relatives (7); other (8); not known (9)

3.2 date at notification (dd-mm-yy)
(not known: all 8)

3.3 date at first symptoms (dd-mm-yy)
(not known: all 8)

3.4 date at clinical diagnosis (dd-mm-yy)
(not known: all 8)

3.5 When did patient first seek medical attention?
(DD-mm-yy) (not known: all 8)

3.6 When was patient referred to a neurologist?
(DD-mm-yy) (not known: all 8)

3.7 vital status of case at time of interview
dead (1); alive (2); not known (8)

3.8 duration of illness
(in months, defined from first symptoms)
(not known: 888)

3.9 date of death (dd-mm-yy)
(not known: all 8)

seen alive

Y/N
### 4.1 Neurological Signs / Symptoms

**Coding:**
- **No (0); Yes (1); Not Known (2)**
  - If yes, record date first seen (dd-mm-yyyy) (not known: all 8)

<table>
<thead>
<tr>
<th>Sign/Symptom</th>
<th>No</th>
<th>Yes</th>
<th>Not Known</th>
<th>Date First Seen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rapidly Progressive Dementia</td>
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<tr>
<td>Cerebellar Signs</td>
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<tr>
<td>Visual Signs</td>
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<tr>
<td>Oculomotor Signs</td>
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<tr>
<td>Pyramidal Signs</td>
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<tr>
<td>Extrapyramidal Signs</td>
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<tr>
<td>Primitive Reflexes</td>
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<tr>
<td>Seizures</td>
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<tr>
<td>Myoclonus</td>
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<tr>
<td>Other Involuntary Movements</td>
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</tr>
<tr>
<td>Headache</td>
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<tr>
<td>Pain</td>
<td></td>
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<tr>
<td>Other Sensory Disturbances</td>
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<tr>
<td>Vertigo / Dizziness</td>
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<tr>
<td>Pseudobulbar Signs</td>
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</tbody>
</table>
4.2  **clinical symptoms/ signs**

- gait disturbances
- speech disturbances
- visual disturbances
- forgetfulness

4.3  **psychiatric symptoms/ signs**

- clinical depression
- social withdrawal
- low mood and apathy
- anxiety
- hallucinations
- aggression

4.4  Since the start of the illness, has the patient been seen by a psychiatrist?
    no (0); yes (1); not known (8)

    If yes, record the date of the first consultation (dd-mm-yy) (not known: all 8)
5.1 Did the patient undergo an EEG?
no (0); yes (1); not known (8)
If yes, on how many occasions? (not known: 88)
If yes, record date of the last EEG (dd-mm-yyyy) (not known: all 8)

5.2 Did the patient record a EEG characteristic of CJD (generalized triphasic complexes with frequency about 1/6s)?
no typical EEG (0); yes, typical EEG (1); no EEG recorded (2); not known (8)
If yes, record the date on which the first characteristic EEG was recorded (dd-mm-yyyy) (not known: all 8)

5.3 Did the patient have a CT-scan of the brain?
no (0); yes (1); not known (8)
If yes, on how many occasions? (not known: 88)
If yes, record date of the last scan (dd-mm-yyyy) (not known: all 8)

5.4 Did the patient record an abnormal CT-scan?
no (0); yes (1); no CT-scan (2); not known (8)
If yes, record the date on which the first abnormal scan was performed (dd-mm-yyyy) (not known: all 8)
If yes, specify what abnormalities have been observed:
no (0); yes (1); not known (8)
- cerebral atrophy
- cerebellar atrophy
- increase in signal density in thalamus
- increase in signal density in (other) basal nuclei
5.5 Did the patient have a MRI scan of the brain?
no (0); yes (1); not known (8)

If yes, on how many occasions? (not known: 88)

If yes, record date of the last scan (dd-mm-yy) (not known: all 8)

5.6 Did the patient record an abnormal MRI scan?
no (0); yes (1); no MRI scan (2); not known (8)

If yes, record the date on which the first abnormal scan was performed (dd-mm-yy) (not known: all 8)

If yes, specify what abnormalities were observed:
no (0); yes (1); not known (8)

- cerebral atrophy
- cerebellar atrophy
- increase in signal density in thalamus
- increase in signal density in other basal nuclei

5.7 CSF findings

- protein (ng/dl)
- glucose (mmol/L)
- cell count (count/mm³)
- 14-3-3 (negative (1); equivocal (2); positive (3))
- NSE (ng/ml)
- S 100b (ng/ml)
- tau (pg/ml)
### 5.8 Has the patient had any abnormal liver function test results recorded?
- **no** (0); **yes** (1); not known (6)

**If yes, please specify:**

<table>
<thead>
<tr>
<th>Test</th>
<th>Normal (9), elevated (1), not known (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>total bilirubin (μMol/L)</td>
<td></td>
</tr>
<tr>
<td>GOT (IU/L)</td>
<td></td>
</tr>
<tr>
<td>GPT (IU/L)</td>
<td></td>
</tr>
<tr>
<td>ALP (IU/L)</td>
<td></td>
</tr>
<tr>
<td>γGTP (IU/L)</td>
<td></td>
</tr>
</tbody>
</table>

### 5.9 Does the patient have any other biochemical/hematologic abnormalities?
- **no** (0); **yes** (1); not known (6)

**If yes, please describe the investigations and abnormalities:**

### 5.10 Did the patient undergo a brain biopsy during life?
- **no** (0); **yes** (1); not known (6)

**If yes, what was the result?**
- no evidence of spongiform change (1); spongiform change without florid plaques (2); spongiform change with florid plaques (3); no biopsy (4); not known (6)

### 5.11 Did the patient undergo a tonsil biopsy?
- **no** (0); **yes** (1); not known (6)

**If yes, what was the result?**
- no evidence of PrP immunostaining (1); equivocal (2); PrP positive (3); no biopsy performed (4); not known (9)
5.12 Post mortem performed?
   no (0); yes (1); not known (8)

   If yes:
   nerve cell loss
   gliosis
   spongiform change
   immuno histochemically positive
   if yes, immunostaining
   Western blot test
   Scrapie Associated Fibris

   If yes, diagnosis CJD confirmed?
   classical CJD (1); nvCJD (2); not known (8)

5.13 Prion protein gene analysis performed?
   (chrom. 20)
   no (0); yes (1); not known (8)

   If yes, mutation present?
   no (0); yes (1); not known (8)

   If yes, specify PRNP mutation

5.14 polymorphism codon 129
   d/M (1); MV (2); VV (3); not known (6)
6.1 How is the patient classified?
sporadic (1); familial (2); iatrogenic (3); new variant (4); GSS (5)

6.2 In patients with sporadic CJD, what is the classification according to diagnostic criteria?
definite (1); probable (2); possible (3)

6.3 If familial CJD or GSS, is the diagnosis based on:
first degree relative with definite or probable CJD?
no relative with CJD (6); relative with definite CJD (1);
relative with probable CJD (2); not known (8)
disease-specific PRNP mutation?
no (8); yes (1); not known (8)

6.4 At notification to the CJDSU, what was the patient’s classification?
definite CJ/D/GSS (1); probable CJ/D/GSS (2); possible CJ/D/GSS (3); diagnosis unclear (4); CJ/D/GSS unlikely (5); definitely not CJ/D/GSS (6); not known (8)
If patient was classified as at least possible CJ/D/GSS, which category of disease was suspected?
sporadic (1); familial (2); iatrogenic (3); new variant (4); GSS (5); not known (8)

6.5 If the patient was seen in live by a member of the CJDSU what was the classification of the patient at the time he/she was first seen by a member of the CJDSU?
definite CJ/D/GSS (1); probable CJ/D/GSS (2); possible CJ/D/GSS (3); diagnosis unclear (4); CJ/D/GSS unlikely (5); definitely not CJ/D/GSS (6); not seen in live by a member of the CJDSU (7); not known (8)
If patient was classified as at least possible CJ/D/GSS, which category of disease was suspected?
sporadic (1); familial (2); iatrogenic (3); new variant (4); GSS (5); not known (8)

6.6 What was the highest classification on the basis of clinical information alone (excluding EEG and CSF)?
probable CJ/D/GSS (2); possible CJ/D/GSS (3); neither probable nor possible CJ/D/GSS (4); not known (8)
Medical history (interview)

7.1 Since 1980 has the subject had dental treatment other than fillings (extractions or root canal work)?
   no (0); yes (1); not known (8)

7.2 Has the subject ever had any operations, including eye operations or stitching of wounds (prior to this admission)?
   no (0); yes (1); not known (8)

   If yes, record number of operations and year of first and last operation (not known: 8888)

<table>
<thead>
<tr>
<th>number of operations</th>
<th>year first operation</th>
<th>year last operation</th>
</tr>
</thead>
<tbody>
<tr>
<td>brain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>spine</td>
<td></td>
<td></td>
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<tr>
<td>other neurologic</td>
<td></td>
<td></td>
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<tr>
<td>eye</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ear</td>
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<td></td>
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<tr>
<td>tonsillectomy</td>
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<td></td>
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<tr>
<td>abdominal</td>
<td></td>
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<tr>
<td>orthopaedic</td>
<td></td>
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<tr>
<td>other</td>
<td></td>
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</tbody>
</table>

COSM Surg.
7.3 Has subject ever received an organ transplant, including cornea or bone marrow transplant?  
- no (0); yes (1); not known (9)

<table>
<thead>
<tr>
<th>Organ</th>
<th>Number of Operations</th>
<th>Year First Operation</th>
<th>Year Last Operation</th>
</tr>
</thead>
<tbody>
<tr>
<td>cornea</td>
<td></td>
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<tr>
<td>bone marrow</td>
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<tr>
<td>kidney</td>
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<tr>
<td>liver</td>
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<td></td>
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<tr>
<td>other</td>
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<td></td>
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<tr>
<td>skin</td>
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</tbody>
</table>

7.4 Has subject ever received a blood transfusion (prior to this admission)?  
- no (0); yes (1); not known (8)

<table>
<thead>
<tr>
<th>Transfusion</th>
<th>Number of Transfusions</th>
<th>Year First Transfusion</th>
<th>Year Last Transfusion</th>
</tr>
</thead>
</table>

7.5 Has subject ever received a transfusion of albumin or immunoglobulin (prior to this admission)?  
- no (0); yes (1); not known (8)

<table>
<thead>
<tr>
<th>Transfusions</th>
<th>Number of Transfusions</th>
<th>Year First Transfusion</th>
<th>Year Last Transfusion</th>
</tr>
</thead>
</table>

7.6 Has subject ever been admitted to hospital because of:  
- bowel disease (1); insulin-dependent diabetes mellitus (2); other (3); never admitted (4); not known (8)
7.7 Has subject ever regularly attended hospital as an outpatient because of:
bowel disease (1); insulin-dependent diabetes mellitus (2); other (3); never (4); not known (6)

7.8 Has subject ever visited his/her GP more than 6 times/year because of:
bowel disease (1); insulin-dependent diabetes mellitus (2); other (3); never (4); not known (6)

7.9 Has subject ever been to see a psychiatrist (do not include consultations for current illness)
no (0); yes (1); not known (8)

If yes, why?
depression (1); psychotic disease (2); other (3); not known (8)

If yes, record number of years and year of first and last treatment (not known: 888)

<table>
<thead>
<tr>
<th>number of treatments</th>
<th>year first treatment</th>
<th>year last treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>medication</td>
<td>ECT</td>
<td>hospitalisation</td>
</tr>
</tbody>
</table>

7.10 Has subject taken any medication regularly, i.e. for a period > 1 months, since 1980 (do not include medications related to current illness)
no (0); yes (1); not known (8)

prompt for prescription drugs?
no (0); yes (1); not known (8)

prompt for hormone therapy or supplements including oral contraceptives and hormone replacement therapy?
no (0); yes (1); not known (8)

prompt for homeopathic/herbal therapy?
no (0); yes (1); not known (8)

prompt for eye drop(s)?
no (0); yes (1); not known (8)

Summary: has subject been exposed to one of the medications of bovine origin withdrawn in 1990? [see list]
no (0); yes (1); not known (8)
7.11 Has subject ever been tested for allergy using needles?
no (0); yes (1); not known (8)
If yes, record number of times and year of first and last testing: (not known: 8888)

<table>
<thead>
<tr>
<th>number of tests</th>
<th>year first test</th>
<th>year last test</th>
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<tbody>
<tr>
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</table>

7.12 Has subject ever received a treatment involving a course of injections (prior to this admission)?
no (0); yes (1); not known (8)
If yes, record name of therapy, frequency and year of first and last treatment (not known: 8888)

<table>
<thead>
<tr>
<th>name of therapy</th>
<th>number of treatments</th>
<th>year first treatment</th>
<th>year last treatment</th>
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<tbody>
<tr>
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</table>

7.13 Since 1980, has subject been vaccinated?
no (0); yes (1); not known (8)
If yes, record type of vaccine, number of vaccinations and year of first and last vaccination (not known: 8888)

<table>
<thead>
<tr>
<th>type of vaccine</th>
<th>number of vac's</th>
<th>year first vaccination</th>
<th>year last vaccination</th>
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<tbody>
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</table>

7.14 Has subject ever undergone lumbar puncture or electrical tests involving needles?
no (0); yes (1); not known (8)
If yes, record number of times and year of first and last puncture or testing: (not known: 8888)

<table>
<thead>
<tr>
<th>number of punctures</th>
<th>year first puncture</th>
<th>year last puncture</th>
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</thead>
<tbody>
<tr>
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</table>
7.15 Has subject ever undergone acupuncture?  
No (0); yes (1); not known (9)  
If yes, record number of times and year of first and last acupuncture: (not known: 8886)

<table>
<thead>
<tr>
<th>number of times</th>
<th>year first acupuncture</th>
<th>year last acupuncture</th>
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7.16 Has subject ever used recreational drugs, for example cannabis, ecstasy, heroin or crack?  
No (0); yes (1); not known (9)  
If yes, record route: intravenous (1); oral (2); inhaling (3); not known (8)  
If yes, record number of years and year of first and last use: (not known: 8885)

<table>
<thead>
<tr>
<th>number of years</th>
<th>year first use</th>
<th>year last use</th>
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7.17 Has subject ever been tattooed?  
No (0); yes (1); not known (9)  
If yes, record number of times and year of first and last tattoo: (not known: 8884)

<table>
<thead>
<tr>
<th>number of tattoos</th>
<th>year first tattoo</th>
<th>year last tattoo</th>
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7.18 Has subject ever undergone ear or body piercing?  
No (0); yes (1); not known (9)  
If yes, record number of times and year of first and last piercing: (not known: 8888)

<table>
<thead>
<tr>
<th>number of piercing</th>
<th>year first piercing</th>
<th>year last piercing</th>
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<tbody>
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</table>
## Family history

<table>
<thead>
<tr>
<th></th>
<th>CJD</th>
<th>OTHER DEMENTIA'S</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>no (0)</td>
<td>no (0); yes (1); not known (9)</td>
</tr>
<tr>
<td></td>
<td>yes, definite (1)</td>
<td>age at onset</td>
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<tr>
<td></td>
<td>yes, probable (2)</td>
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<tr>
<td></td>
<td>not known (9)</td>
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<tr>
<td>father</td>
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<tr>
<td>mother</td>
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<tr>
<td>grandmother father</td>
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<td>grandfather father</td>
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<tr>
<td>sibling 12</td>
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</table>

8.2 Has the subject had social contact, through family, friends or work, with someone else who developed CJD?
- no (0); yes (1); not known (9)

If yes, record the person's approximate date of illness (dd-mm-yyyy) (not known: all 9)

Confirmation of social contact with case of CJD
- definite (1); probable (2); possible (3); unsure to concern (4)
- not a case (5); not known (9)
Dietary history

9.1 Has subject ever been a vegetarian for a period of 1 year or more?
   no (0); yes (1); not known (8)
   If yes, during what period?
   before 1980 (1); 1980-1985 (2); 1985-1990 (3); 1990-1996 (4); not known (8)
   more than one option possible
   If yes, for how many years? (not known: 88)
   If yes, did (s)he eat any meat or fish at all during this time?
   no (0); yes (1); not known (8)

9.2 Since the beginning of 1980, has subject ever eaten cat or dog food?
   no (0); yes (1); not known (8)
   If yes, how?
   tinned (1); dried (2); tinned and dried (3); not known (8)

9.3 How does/did subject like his/her steak cooked?
   well done (1); medium (2); medium rare (3); rare (4); did not eat steak (5); not known (8)

9.4 For each of the following food items how often did subject eat the food item, on average, since the beginning of 1980? Ask respondent to indicate the most appropriate response from those shown on the flash card.
   please code origin: beef (1); pork (2); lamb (3); horse (4); chicken (5); veal (6); venison (7); not known (8) more returns possible

   freq. brains √ eyes √ tripe √ liver √ raw meat
Goat (meat/cheese)

- kidneys
- sweetbreads (pancreas)
- readymade burgers
- readymade meat pies such as pork, veal and ham, steak and kidney, chicken and mushroom
- meat sausages
- black pudding
- liver sausage or paté
- steak tartare (raw minced steak with raw egg/carpaccio)
- cheese
- roast lamb, lamb chops, lamb stew
- haggis
- roast pork, ham, bacon
- faggots
- roast beef, steak, beef stew, minced beef
- veal
- venison
- chicken
- cow's milk

Drinks: milk with breakfast cereal (1); only in tea/coffee (2); no (3); not known (6)
10.1 Since the beginning of 1980, has subject shared a home with:

- cats
  - no (0); yes (1) not known (9)
- dogs
  - no (0); yes (1) not known (9)
- ferrets
  - no (0); yes (1) not known (9)

10.2 Since the beginning of 1980, has subject worked on or stayed for more than one week on a farm?
- lived or worked (1); stayed (2); no (3); not known (8)
  - If yes, did subject work or help with:
    - cattle
      - no (0); yes (1) not known (6)
    - sheep
      - no (0); yes (1) not known (6)
    - goats
      - no (0); yes (1) not known (6)
    - pigs
      - no (0); yes (1) not known (6)
    - chickens
      - no (0); yes (1) not known (6)
    - mink
      - no (0); yes (1) not known (6)
    - deer

  - If yes, did subject participate in:
    - treating cattle for warble fly (with phosmet)
      - no (0); yes (1) not known (6)
    - clipping sheep
      - no (0); yes (1) not known (6)
    - crop spraying
      - no (0); yes (1) not known (6)

10.3 Since the beginning of 1980, has subject used any of the following:

- bonemeal
  - no (0); yes (1) not known (6)
- hoof and horn
  - no (0); yes (1) not known (6)
- dried blood
  - no (0); yes (1) not known (6)
- manure
  - no (0); yes (1) not known (6)
0.4 How often does/did subject cut or chop up raw red meat or bones, in his/her work or at home? Ask respondent to indicate the most appropriate response from those shown on the flash card.

0.5 Has subject ever dissected animal eyes, for example at school? no (8); yes (1) not known (9)
## Occupation

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.1 Has the subject ever worked in farming, the meat industry, the pharmaceutical industry or in a hospital</td>
<td></td>
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<tr>
<td>11.2 Has subject worked in the following areas:</td>
<td></td>
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<tr>
<td>medical/paramedical/nursing/dentistry</td>
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<tr>
<td>animal laboratories</td>
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<td></td>
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<tr>
<td>pharmaceutical laboratories</td>
<td></td>
<td></td>
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<tr>
<td>other research laboratories</td>
<td></td>
<td></td>
</tr>
<tr>
<td>animal farming/veterinary medicine</td>
<td></td>
<td></td>
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<tr>
<td>(butcher's/abattoir/underling plants etc)</td>
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<td></td>
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<tr>
<td>catering industry</td>
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<td></td>
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<tr>
<td>other occupation involving animal products (e.g., leather worker)</td>
<td></td>
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<tr>
<td>hunting</td>
<td>Y/N</td>
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<td>11.3 Has subject's partner worked in the following areas:</td>
<td></td>
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<tr>
<td>medical/paramedical/nursing/dentistry</td>
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<tr>
<td>animal laboratories</td>
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<td>pharmaceutical laboratories</td>
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<tr>
<td>other research laboratories</td>
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</tbody>
</table>
11.4 Was subject’s parents’ most recent occupation in any of the following areas:

- Animal farming/veterinary medicine
- Meat industry (butcher’s/albatar/ rendering plants etc)
- Catering industry
- Other occupation involving animal products (e.g. leather worker)

- Hunting: yes/no
Residential History:
## Coding for food frequencies

<table>
<thead>
<tr>
<th>Response</th>
<th>Code</th>
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<tbody>
<tr>
<td>Never</td>
<td>1</td>
</tr>
<tr>
<td>less than once per year</td>
<td>2</td>
</tr>
<tr>
<td>about once per year</td>
<td>3</td>
</tr>
<tr>
<td>several times per year</td>
<td>4</td>
</tr>
<tr>
<td>about once per month</td>
<td>5</td>
</tr>
<tr>
<td>about once per week</td>
<td>6</td>
</tr>
<tr>
<td>several times per week</td>
<td>7</td>
</tr>
<tr>
<td>several times per day</td>
<td>8</td>
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</tr>
<tr>
<td>1</td>
<td>General Information</td>
</tr>
<tr>
<td>2</td>
<td>Identification control</td>
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<td>Dietary history</td>
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<td>11</td>
<td>Occupation</td>
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<td>Coding for food frequencies</td>
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