Total Sheets

Fill in the total number of Personal Details sheets used for any one parent in the total sheets box.

Personal details

Name

Probe for changes of name of child, and parents, check that all of the child's first names are given, and that all previous names used have been obtained. In particular ask for maiden and all married names of the mother.

Address

The address at diagnosis is recorded on the Registration sheet (if the case or control was on holiday or staying briefly elsewhere at the time of diagnosis, this is ignored.) For people who have recently moved it is imperative that the previous address is recorded on the Registration sheet in order to identify an FHSA to select controls. NB - FHSA areas are made up of local authority areas so ensure that you record the local authority area correctly.

GP Details

GP name - Fill in both the name of the doctor, and of the practice with which he or she is associated. BE sure to record both your informant's GP, their partner's GP where relevant, and the GP caring for the index child.

Section I

General background

Mother/ Father

Page 1

Q 1 (a) - Natural mother

This means biological mother, ie the woman who conceived and bore the child. If your informant is unsure about your meaning -

PROBE

I mean, is your own child?

Q 1 (b) - When did first come to live with you.

Record the first date, even if this was only for a short time. If the child moved away again, and then came back, make a written note to this effect.

For non-biological parents only a subset of the questionnaire is asked. Please see the separate set of instructions for this. In most cases you will know before the interview, and will be able to prepare accordingly, but this can't be guaranteed.

Q 2 (a) - 'Living away from you for longer than six months'

...means times when the child's main residence was different from your informant's for more than six months, even if your informant saw the child regularly, or the child came to stay with your informant for some short periods of time during the six months in question. If in doubt write it down. If there were more than two such periods continue on further copies of this sheet, following the instructions in Section 10 of the general notes.

Q 2 (b) - Record date or age of index child.

Section 1 General background Mother/ Father

Q 4

Read through the list as written until stopped by your informant.

Q 5 Ethnicity

Begin reading list and show the prompt card to your informant. Please do not argue with your informant, even if what they say appears to be incorrect.

O 6

This means the age when your informant first stopped full time continuous schooling, usually to start work, occasionally to get married, even if he/she went back to it later on. This refers to secondary level education of some kind, and accordingly most people will say 16, and most of the rest will say 17 or 18. It does not mean age on leaving full-time education, although for most people the two are the same. Anyone who has left school for more than a year, even if they later return, unless this was due to ill health, should have their age at the first leaving recorded here. Fill in any further details offered by your informant.

PROBE I mean secondary school.

Q 7 Educational Qualifications

Enter yes or no in each of these boxes. Obtain detail only for the 'higher' qualification. Record qualifications mentioned by your informant, even if they don't appear on the list provided. For foreign school or technical qualifications try to get the age when, and the country where they were done.

PROBE Did you ever do any exams, or get any qualifications?

Q 8 Tenure

Housing association includes housing co-operatives, co-ownership and cost housing or fair rent schemes. The Scottish Special Housing Association is a local authority scheme, and is coded as such. Under other please put tied housing, families living rent free with in-laws, and people in LA or DSS funded B&B accommodation.

Section 1

General background

Mother/ Father

Q9 Paid job

This means any paid activity whatever, even if payment is purely on commission. Part time work is included. Voluntary work, or work for expenses only is not 'paid'.

Job Title

Probe for precise job title. Replies such as clerk, manufacturer or engineer are too vague and can't be coded. The exact work done, and the nature of the industry, or place of employment are both needed. For someone on a YOP/YTS etc. scheme, record the scheme, but also determine the industry and the job title. For apprentices record the fact that your informant is an apprentice, but also what exactly they are apprenticed to. Please give the fullest possible details. For managers it is critical for successful coding to know what type of business they are managing. For civil servants please record both grade and job title.

PROBE

Can you tell me exactly what you do/did?

What kind of firm did you work in?

What did they make or do?

Q 11

This asks about the product of the organisation, not the product of your informant's work, so for a cleaner in a steel works, record steel production here. Please give the fullest possible details.

Q 12

PROBE

Did anyone report to you?

Were you responsible for anyone else's work?

Q 12 and Q 13

The number of employees/persons supervised is only needed for social class coding. If someone supervises or employs more than 98 people, just fill in 98, and this will suffice.

Section II

Residential history

Mother/ Father

Complete one of these sheets for every residence listed on the Pre-interview questionnaire, starting with the house in which your informant was living one year before the index child was born, and continuing to the present. Even if your informant knows nothing whatever about the house fill in a sheet. Put the Residence number from the pre-interview form in the box provided on each sheet.

If your informant remembers a house, which isn't on the pre-interview form, please write it on the pre-interview form yourself, adjusting the dates recorded for the other houses and the residence numbers as necessary. This means that the residence numbers will not be in date sequence, but this doesn't matter.

Q 2

Flat includes flats in converted houses, as well as purpose built blocks of flats. Other includes hostels, digs, hotels, B&Bs, etc.. The distinction is that a flat has its own cooking and toilet facilities.

Basement means any floor which is below the usual ground level on both of its longer sides. The room, common in some cities, which is at or above ground level on one side, and two or three stories below it on the opposite side, is not a true basement, and should be coded as Other.

Q 3

The main living area is the room in which most of the family activity takes place, rather than the living room as such. Often the answer will refer to the kitchen.

PROBE I mean the room in which the family spends most time.

Q 5 to Q 8

In each case the If yes: means if yes to the main stem, ask was it there when you moved in. The If no: means if it wasn't there when you moved in, do you remember when it was installed? For these questions answer yes if any of the relevant rooms had central heating or double glazing.

Double glazing means any form of glazing with two or more panes of glass. This includes so-called secondary glazing, with unsealed extra panels.

Central heating means any form of heating in which two or more rooms are heated by the same type of heating appliance, and specifically includes heating more than one room from one coal burning fire and electric storage heaters.

Q 9

PROBE Do you just have the usual water supply from the company?

If they have more than one water supply, ring Other and describe the precise circumstances. Water from a "bore hole" should be coded as well-water.

Section II

Residential history

Index child

Complete one of these sheets for every residence listed on the Pre-interview questionnaire, in which the index child has ever lived, even if the child lived there for a very short time, starting with the house in which your informant was living when the index child was born, and continuing to the present. Otherwise follow the instructions as for the informant's residential history.

If the index child never lived in this house skip p8 (residential history:2) and continue on p9 (residential history:3)

0 11

Room includes any habitable room, all kitchens, even if only used for cooking, but it excludes rooms only habitable for part of the year, like some conservatories, and rooms not normally used for living purposes, like toilets, bathrooms, hallways, garages, cloakrooms, store rooms etc.. Any room shared with another household counts as half a room. If in doubt as to whether or not a room should count, include it.

If additional rooms have been built during the period of residence record the number at the time of leaving (or the present).

Q 12 and Q 13

This means anyone who is regarded by your informant as having the address in question as their main residence at any time during the period when the family lived there. Children under 16 are included, even if at boarding school, but children over 16, if living away from home, eg for study or work are excluded. Foster children and others who resided there for more than three months are included. Record the maximum number of persons who lived there for at least three months at any one time.

Q 13

Total number of children includes index child.

Q 14

If no - please record on which floor the index child slept for most time at night.

Q 15

Try to identify the sharer, so that they can be picked out from the person lists later on. Please put both a name, and a relationship here. Remember that these children will have to be allocated person numbers later on, so give fullest details.

If you have to fill in more than one sharer for the bedroom, continue to fill in question 15 using one line per person and the dates applicable. If you need to fill in "other times" when the index shared a bedroom with someone at the same residence and need further sheets put the residence number in the box provided leaving the other questions blank and complete Q15 as already stated. Group the simultaneous times together and write "sharing with more than one person" underneath the last one. When ID numbers have been allocated, fill them in in the box provided. Code the sharer with either a P,F or 8 number at blue edit depending on the type of relationship etc - see Interviewer Instructions/Coding Manual.

Complete one of these sheets for every residence listed on the Pre-interview questionnaire starting with the house in which the informant was living one year before the index child was born and continuing to the present.

Put the residence number from the pre-interview questionnaire in the box provided.

- Q16 These chemicals may include pesticides, insecticides or fungicides depending on the condition being treated.
- Q17 Record the date or the age of the index child.

Mother/ Father Section III Employment history

On the pre-interview questionnaire circle the code number for each exposure mentioned there for each job, obtain further details, if necessary, of the job itself and the place of work (industry).

Using the pre-interview questionnaire go through your informant's occupational history. We are interested in jobs which lasted at least six months. For the purposes of these questions very similar jobs of short duration should be amalgamated together, thus jobs done by a person who worked as a casual labourer, assembly line worker, kitchen help etc., doing a few weeks here and a few weeks there would be counted. Someone working as a temp or locum with an agency is employed by the agency for the duration of their period of temping and this should be counted as one job.

For anyone doing the same job but in many different settings then ask a simple question— Did any of these jobs involve you in handling or being exposed to...

Employer's (name and address): ensure that details of what the organisation/employer "makes or does" is written on the pre-interview form; eg plumbing contractor, metal foundry, vegetable shop, produced moulded plastics, engineering company producing metal 'parts', wood yard-distributing, storing and cutting timber.

If your informant is unsure of the chemical nature of substances to which he/she may have been exposed, try to get trade names, common names, workplace names, nicknames etc... for them. Even if you are sure that your informant is wrong, please write down what they say. Proprietary mixtures change their contents more than their names.

01 Note - Some adhesives contain solvents Solventrs include alcohol methylated spirit and acetone.

Q3 Dyes or Pigments

> PROBE Colouring agents?

Petrol, etc.

PROBE Diesel or other fuels?

Q6 Fertilizers, etc.

> PROBE Weed killers, Insect killers, Things to treat fungus rots in wood

and so on?

Radiation

Ultraviolet light, ultrasound, laser light, microwaves, and radar waves are not ionizing radiations.

PROBE Did anyone at your work use X-ray machines, for example to take pictures of the inside of machines, or castings?

Did you use any radioactive isotopes or tracers at work?

Did anyone at your work wear film badges, or radiation protec-

tion clothing at any time?

Section III Employment history

Mother/Father

Exposure record

Fill in the job number at the top of each section.

There should be at least one exposure record for every code circled on the pre-interview form. Thus if in one job your informant was exposed to five different types of exposure there should be five separate exposure records completed, recording the same job No. with the relevant exposure No...

If your informant was exposed to several different chemicals or types of radiation from one group, fill in one exposure record for that group. Write down all further available information on Page 11. The more information available the better.

For each category of exposure try to get as full a list as possible of the chemicals involved.

PROBE

What was used for?

Were any other similar chemicals in use there?

Q3 This question, for the reasons mentioned above will often elicit the response 'Nothing' from women, and from men in non-manual posts. However if they passed through production areas, or worked close by they will often have been exposed, so -

PROBE

How often did you come into contact with?

Did you ever get any of it on you?

Could you smell it from where you worked?

Q 5

Radiation monitoring usually means Film badges, which are small badges, currently made of blue plastic, worn on outside clothing, and sent off to be developed once a month or so. Nuclear workers will be very aware of how they were monitored, other workers may be much less clear*.

There are other forms of monitoring, including whole body measurement, and surface monitoring. Blood and urine tests are occasionally done for specific incidents of contamination. Outside the nuclear industry these are relatively uncommon.

PROBE

Did you have any radiation records or cards?

^{*}If someone was monitored in more than one way, mark Other and give a full description.

Section IV General health Mother/ Father Illness

Most people who have had the illnesses mentioned will be clearly aware of the name and nature of the illness.

PROBE

- 2) Thyroid disease or Graves' disease or Goitre of some type?
- 4) Permicious anaemia may be distinguished from the far commoner ordinary (iron deficiency) anaemia by the need for regular vitamin B12 injections, usually once a month.

PROBE Did you need any regular injections for your anaemia?

- 6) Multiple sclerosis or MS or disseminated sclerosis or DS?
- 11) I mean had blood given to you in hospital?

(To avoid confusion with blood donation)

Fill in the total number of positive responses to these questions in the box provided, and complete one illness record for each positive response.

PROBE Have you ever needed to take tablets or other medicine for a long time?

Section IV General health

Mother/ Father

Mness

Fill in the page number at the top starting from 1.

Under condition write the 1 or 2 digit code from the general health sheet in the two white boxes. Put as much detail of the diagnosis as you can get on the line.

Condition

For Diabetes the essential question is

PROBE

Did you need insulin?

For *Blood transfusions*, please identify the illness for which it was given. Common reasons include surgery, after an accident, and so on. Note that you should fill in an illness record for each occasion on which a transfusion was given.

PROBE Why were you given blood?

Section V X-ray history

Mother/ Father

Page 1

Note that this question refers to any X-rays in the mother's life before she became pregnant with the index child or in the father's life before the index child was born, not just to X-rays taken shortly before the child's birth, which are covered again later on.

When asking this question read out each line slowly. Pause after the 'medical name' of the X-ray, and again after the 'explanation'. You must ask about every type of X-ray.

1) Fluoroscope: this is a technique where the X-ray is displayed "live" on a screen. It is usually used to look at breathing, swallowing or movement. The shoe shop/ foot X-ray is excluded.

- MRI scans are becoming more common. The point is that you are put into a huge magnet, and pictures are taken, using radio waves, of the inside of your body. This is similar in concept to a CT scan, except that no X-rays are used.
- Insufflation, or salpingography, is occasionally used as part of the investigation of infertility. The injection of dye is made through the cervix, or neck, of the womb.
- Pelvimetry, is a series of x-rays of the lower abdomen used to determine the size of the pelvic canal for delivery. This may be done in late pregnancy, during labour or post-natally. Only record the event in non-index pregnancies.

Abbreviations

CT Computed Tomography

CAT Computed Axial Tomography

MRI Magnetic Resonance Imaging

NMR Nuclear Magnetic Resonance

Section V >

X-ray history

Mother/ Father

Detai

Fill in the page number at the top of each sheet starting with 1.

Q 1

Fill in the 1 or 2 digit code from the general X-ray sheet in the two white boxes. Ask the respondent to describe the X-ray procedure and record details.

Q 2

Fill in one detail sheet for each occasion on which the specified type of X-ray was done. Thus a person who has had three Barium meals will have three X-ray records, each with the code 03.

04

Do not ask this question if the answer is obvious from the type of x-ray involved (eg barium enema or cholecystogram).

Q 5

Please get as much detail as possible, including address of hospital if known.

Section VI S

Social habits

Mother/ Father

Q1

If the answer to Question 1 is NO, skip the rest of this page, and go on to Section VII, Obstetric history.

For each type of tobacco smoked regularly fill in the relevant section across.

Q 2

The aim of these questions is to get a picture of the informant's usual pattern of smoking, before and after the birth of the index child, and if they still smoke, to see how much they smoke now.

If they still smoke, ask the three questions in 2a - i, ii, and iii, covering the year before the index child's birth, the year after, and the present day.

If they don't smoke now, ask the next question 2b-i, and then ii. If they stopped smoking before the index child was born, ask question 2ba - i, ie how many they were smoking one year before that event. Note that if they stopped smoking more than one year before the birth, the correct answer to this section will be 0.

If they don't smoke now, but were smoking when the child was born, ask questions 2bb - i and ii, covering one year before the birth, and one year after.

Note that in certain circumstances, e.g. a very young index, these parts may overlap, and some may need to be adjusted to make sense. So for a nine month old child 'one year before birth', and 'one year ago' make sense, but overlap, and 'one year after birth' is meaningless.

Section X

Family illness

Page 1

Take the pregnancy number from the mother's Obstetric history sheet. One column should be filled in for each child, who has the same father, or mother as the index child.

Other children living in the household are not of interest for this question. Clearly if your informant tells you that one of her step-children has had leukaemia, for example, do not tell her that you are not interested, but simply write it down, and you can remove it at the blue edit.

Children who have no pregnancy number because they share a father only with the index child should be given numbers starting with F1. Only children sharing a parent with the index child are included.

You may require more than one sheet for large families, if so follow the instructions in Section 10 of the general instructions.

Section X Family illness

Page 2

The illness number ranges from 1 to 10, depending on which illness the sibling had.

Section XI Employment in specific industries

Q 1

Fill in the appropriate industry name from the CHECK LIST.

02

Get as much detail of the job as possible.

Job title

Probe for precise job title. Entries like clerk, manufacturer or engineer are too vague. The exact work done, and the industry are needed. For someone on a YOP or YTS scheme, record the scheme, but also determine the job title.

PROBE Can you tell me exactly what you did?

Q 3-5

Write down full details of any other monitoring procedures used.

If someone worked in the same industry at several different times, or in several different jobs, fill in a record for each job, and each period of employment. If you require more than one sheet, please follow the instructions in Section 10 of the general instructions.

Request for permission

Emphasise to prospective signatories that all information collected will be held in strictest confidence; that no one outside the research team will be allowed access to it; and in particular the people approached for further information will not be given any information disclosed by your informant during the interview.

Section XII Further information

Q1 Record the date of the earliest symptom which your informant associates with the child's illness.

Fill in the time at the end of the interview here (24 hr. clock).

Interview evaluation

Name

Fill in your personal code here as well.

Surrogate information

If you obtained information about the mother's history or the child's from anyone except the mother, please mark Yes, and indicate the name of your informant, and his/her precise relationship, both to the mother, and to the index child. For the father's history do the same. Briefly note why surrogate information was required. This information will be essential when it comes to analysis of the questionnaire later on.

Mode of interview

This will usually be face to face, but telephone interviews, and even postal interviews are possible.

Other persons present

This is also very important for analysis, and should be filled in afterwards. We are particularly concerned to record this if the person present was the other informant, eg if mother and father were interviewed together.